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UNIVERSITY OF ALBERTA

EXPLORING HOPE WITH CHILDREN LIVING WITH CANCER

BY

SUSAN M. DANIELSEN



A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY

IN

SCHOOL PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

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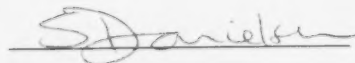
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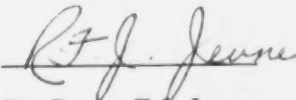
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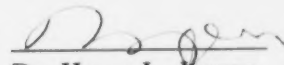
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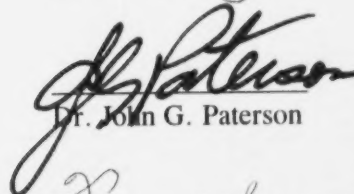
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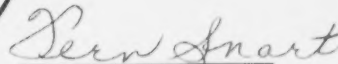
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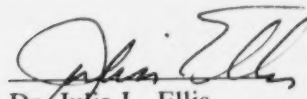
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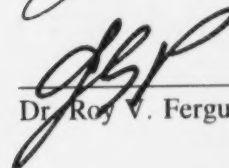
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This hope exploration is dedicated to the children whose
stories are the pieces of hope, the children behind the
names...

CURTIS

JESSIE

MICHAEL

Thank you for sharing your pictures, your wisdom, your
courage and your smiles!!

and to

TYLER

...for the colorful paintings which brighten my office

...for sharing your journey and your spirit

...for calling me your friend

Thank you for helping my hope!!

And to all of your parents and brothers and sisters who
nurtured the hope you shared here with me.

My hope for each of you is continued health, love and
laughter.

ABSTRACT

Awareness of hope as a vital ingredient in the treatment of pediatric cancer is increasing, yet a striking contradiction remains in both the medical and psychological literature. Although hope is viewed as essential to children with cancer, there is little inquiry into what hope is to children.

This study explores children's hope using a qualitative research methodology. It provides a beginning exploration of hope from the child's perspective, specifically the child living with cancer. Its purpose is to provide preliminary information about hope based on a small sample of children. The hope explorers are four children between the ages of six and nine who received treatment both as inpatients and outpatients at a regional cancer hospital.

The children were invited to explore hope during two individual interviews through painting, drawing, story and dialogue. Hermeneutic phenomenology is the methodology used to guide the interviews, analysis and interpretation of the data. The children's pictures and ideas about hope are presented and serve as a basis for thoughtful reflection and interpretation. Together with the researcher, the children explore such topics as "Mom the hopemaker", "Hoping and wishing", "Dogs and gummy bears; Hope helpers", "Good hope and bad hope", to name a few. The children present several important messages: 1. Hope is essential to a child living with cancer. 2. Having cancer and enduring invasive treatment, hospitalizations and painful procedures makes it very hard to hope. 3. When it is hard to hope, children need outside assistance to help the hope that lives inside them.

Based on those messages, the researcher provides reflections and suggestions on how parents and health care professionals might better understand and connect to the hope of children. Perhaps weaving an increased understanding of children's hope into our own lives might allow us to respond to children more hopefully. Hypotheses for further research are also generated.

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Hope is a song of believing, of reaching for dreams and of never giving up. Once you have it, it will never leave you... for it becomes a part of what you are.

(Flavia Weedn)

Dr. Ronna Jevne

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Casey

For always listening and understanding...

Mom, Dad, Reid & Omi

For believing in me...

♥I thank you.♥

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I. INTRODUCTION

I've been needing, needing more hope for all this year that I have cancer.

(Tyler, age 6)

Increasing awareness of hope as a vital ingredient in the treatment of cancer has been emphasized by recent research (Goertzel & Goertzel, 1991; Hinds, 1988; Saba, 1991). As a psychologist working with children in a health care setting, I am constantly seeking better ways to help children cope with challenging events in their lives, particularly those children living with chronic or life threatening illness such as cancer. As I strive, through therapy, to help children come to a better understanding of their own experiences, I am continually amazed by the children's fortitude and positive outlook on life.

How do these children cope with their circumstances? What keeps them going? What essential elements underlie their approach to life, or precede their ability or even their desire to cope? Concepts such as resilience, self esteem, hardiness, optimism and self efficacy have been proffered as possible clues, yet the related, more encompassing domain of hope has been ignored.

Hope, despite being recognized as "essential to counselling", and "necessary for healing" (Jevne, 1990, p. 26) remains a complex, intangible concept which researchers hesitate to address. Hope pervades such disciplines as medicine, psychiatry, philosophy, theology, nursing and psychology, and has been identified as a vital human phenomenon worthy of investigation (McGee, 1984; Hinds, 1988), yet the topic has not been adequately explored with adults, let alone children.

As the literature review will show, there is a contradiction in psychological and medical literature; hope is viewed as vital to children with cancer, yet there is little inquiry into what hope is to children. By listening to the children, and exploring hope with them, I intend to address this dearth and help the children present hope from their perspective.

Studying hope from a child's perspective requires an understanding of the way children experience the world. My view is presented and clarified below.

Children have something to share with us about hope which is worthy of recognition and consideration. Based on years of watching, listening, interacting with,

and simply being with children in educational, therapeutic, and personal situations, I have come to value and respect their refreshing and honest insights about their world. We often speak of "the innocence of childhood" or wish we could once again "see the world through the eyes of a child". While these are everyday figures of speech, they have their origin in the intuitive adult notion that somehow children see the world differently. Erikson (1977) writes that

Freud, who never worked with children clinically, but deeply treasured their company in daily life, noted with bitter sadness what the process of growing up makes of what he called "*die strahlende Intelligenz des Kindes*": the radiant intelligence of the child. And those of us who have observed children's play, including that of child patients in acute emotional conflict, have never been able to hide some rather elemental joy in seeing children look and speak, play and act with an originality and wholeness recovered only in creative moments in later life. (p. 54)

Perhaps it is in the originality and wholeness of childhood that adults see a reflection of what we strive to recapture as we search for meaning in our own lives. We recognize in childhood a certain truth value. By uncovering children's lived experiences of hope, we might in turn enhance our own understanding of hope. As Van Manen (1990) questions, "Where is the common sense, the sense in common, the basic assumptions and values that constitute the indices of the rich resource, the inexhaustible layers of meaning, of everyday living with children?" (p. 142). Children have much to teach us, if only we take the time to listen and learn.

Children experience the world in a way that is qualitatively different from adult experience. "Knowledge without love, respect, and admiration for the being of a child cannot come to a full understanding of the child" (Van Manen, 1990, p. 140). In order to have love, respect and admiration for the being of a child, we must attempt to uncover what that being is like for children. How do children experience the world? What is unique about children's experiences, or their way of knowing? How is their experience different from that of adults?

For children the world is a playground of possibilities. They approach each moment with a new sense of wonder and are constantly encountering new, previously undiscovered, aspects of their world. Children live in the realm of the not yet realized

or experienced; hope appears inherent in such a world. Marcel (1951/62) writes that "hope is engaged in the weaving of experience now in process, or in other words in an adventure now going forward" (p. 52). What is more an adventure, or a seeking of new experiences than childhood itself? Marcel (1951/62) also asserts that it is adults, who have already experienced much of life, that impede or lessen the hoping of children:

How can we help remembering here the impression, rightly termed *hopeless*, which every child and adolescent has received when his elders pronounce one or other of those axioms which claim to express *truths which are indisputable* and duly established. Such axioms seem to strike out of existence all the dreams, all the confused aspirations of him who not having had *his own* experience refuses to accept a so-called proof with which he is in no way associated. (p. 52)

The way children experience the world has implications for working or living with children. As Rousseau (1762/1979) wrote centuries ago, "childhood has its own ways of seeing, thinking, and feeling which are proper to it. Nothing is less sensible than to substitute ours for theirs" (p. 90). Without an understanding of hope from a child's perspective, when we speak of children and hope, we are forced to do so from an adult perspective. This may be misleading, as an "adult's understanding of a child's experiences has something to do with the way this adult stands in the world" (Van Manen, 1990, p. 137). By placing adult categories on childhood experience, we risk failing to interact with children in a manner which is true to their experience of the world.

The purpose of my research is to explore and present hope from the child's perspective, specifically the child living with cancer. Phrased differently, what is the nature of hope for a child living with cancer? How do children experience the phenomenon of hope? What are their unique expressions of hope, their symbols, their images?

This research is only a beginning exploration of children's hope. Its purpose is to provide preliminary information about hope based on a small sample of children. My intent is to present innovative and thought provoking material with the anticipation that this initial inquiry may generate further research aimed at understanding hope in children. For me these children literally embody hope, and it is my belief that they

have much to share with us about how we might better help them sustain or enhance that hope.

II. REVIEW OF THE LITERATURE

Things past belong to memory alone; Things future are the property of hope.
(John Home)

In 1959, Menninger referred to writings about hope by saying that "when it comes to hope, our shelves are bare. The journals are silent" (p. 481). A recent review of current hope literature suggests that the journals are beginning to speak, if only at a whisper. A comprehensive review of hope writings in philosophy and Christian theology, as well as theoretical and empirical research in psychology, psychiatry and nursing was compiled by Dufault in 1981 as part of her doctoral dissertation Hope of elderly persons with cancer. Dufault's detailed, critical review remains unsurpassed, respected and well cited more than ten years after its publication. With appreciation for Dufault's thoroughness and insight, I refer the reader seeking an extensive journey through the history of hope literature to her work.

The purpose of this chapter is to examine existing literature and research relevant to the exploration of hope from the perspective of children. In addition, I intend to illuminate the writings and ideas I have been most attracted to in framing my approach to hope, especially as it is lived by children.

Following a multidisciplinary consideration of what hope might be, this presentation will focus on aspects and dimensions of hope which are essential prerequisites to exploring the hope domain with children. Specific attention will be given to theoretical views on the development of hope, to research findings related to children and adolescents, and to hope's importance in relation to cancer or other life threatening illnesses. Finally, a critical evaluation of available literature and research will lead to an understanding of the need for my approach to hope inquiry.

Hope Is...

What is hope? Each of us has an intuitive knowledge or understanding of what is meant by the word hope. We can all talk about hope, point out possible examples of it, and use the word in sentences, yet it seems a notion we can never fully grasp. Merely attending to its use in language, and reading different authors' attempts to

define hope leads to the realization that as soon as we begin to search for the essence, or true meaning of hope, it becomes more elusive.

Endeavours to convey the real meaning of hope, or to define it are evident across disciplines. There appear to be as many "hope is..." statements as there are individuals studying or experiencing hope. Not surprisingly, each discipline tends toward its own language for hope, and uses metaphors for and images of hope consistent with that discipline.

Theologically, hope is referred to as a state of waiting, of "unfulfillment that looks forward to fulfillment" (Meissner, 1973, p. 12). Christian hope is eschatological, being rooted in the promise of salvation (Moltmann, 1967), and is considered "an essential and dynamic element in religious motivation" (Meissner, 1973, p. 7). God is the ultimate and only possible source of hope in much of theology (Marcel, 1951/62; Moltmann, 1967). Placing hope in an infinite being allows hope to be referred to as "a mystery" (Marcel, 1951/62, p. 35), "a light yet to be born" (p. 31), and something that springs eternal from the depths of one's being (Vaillot, 1970).

Nursing literature naturally speaks of hope in relation to health issues (Dufault & Martocchio, 1985; Herth, 1991; Hinds & Gattuso, 1991). Herth (1991) perhaps best summarizes many of the current attempts to convey what hope is within nursing when she writes of hope as "a multidimensional resource that contributes to adaptive coping during illness, and positively influences wellness" (p. 39). Hope is also viewed as an "anesthetic or an insulation in the midst of hardship" (Dufault & Martocchio, 1985, p. 385), a "vital dimension that helps solve human problems" (McGee, 1984, p. 39) and "a contributing factor in health maintenance" (Hinds, 1988, p. 79).

Literature from psychology and psychiatry also has its hope language. Hope may be expressed in terms of expectation, goal attainment and positive affect (Frank, 1968; Snyder et al., 1991; Snyder, Irving, & Anderson, 1991; Stotland, 1969), but can also be seen as "another aspect of the life instinct, the creative drive which wars against dissolution and destructiveness" (Menninger, 1959, p. 483). Lynch (1965) asserts that to "have the image of oneself as human is the beginning of hope" (p. 211), while Erikson (1977) refers to hope as "the first psychosocial strength essential for ego development" (p. 50).

Clearly, hope touches each of these disciplines, yet it is referred to with a multitude of different words and images, and is seen from different perspectives, including the spiritual, physical, and psychological. Perhaps each of the above descriptions reflects hope, or perhaps hope is a combination of the various portrayals; despite the vast number of possibilities, there is no consensus in the literature regarding a definition or description of hope.

Also, the literature that is available on hope comes from two perspectives. Academic literature has been written almost solely from the point of view of the scholar or professional. Rarely is the information presented from the perspective of the individual who is experiencing hope or who lives in a hope challenged state. In contrast, popular "beyond all odds" stories, novels and biographies express the experience of hope, but lack a professional view. The two perspectives are never bridged; the experience is missing in one, the scholarly in the other (R. Jevne, personal communication, May 4, 1993).

This lack of agreement on the very nature of hope makes inquiry difficult, although it is not of primary concern to my research. I am seeking to explore what hope is for children, and will not be using the literature definitions as a starting point for research. What does have important implications for my research, is the fact that there is little literature or research which has focused on hope from the perspective of children. The above definitions derive from theorizing about hope, and from research conducted with adults. Before examining the literature related to children and hope, a brief presentation of the development or origin of hope is necessary.

Development of Hope

Hope "has a history and a course of development" (Meissner, 1973, p. 22), which is most specifically referred to by Erikson (1977, 1964, 1950). Erikson incorporated hope into his theory of psychosocial development, or *The Eight Ages of Man*. Hope begins to develop during the first stage of life when an infant is able to build a trusting relationship with its first maternal caregiver. Following positive resolution of this first Basic Trust versus Basic Mistrust stage, Erikson ascribes "to the healthy infant the rudiments of *Hope*" (1964, p. 115). He continues, to say that

it would, indeed be hard to specify the criteria for this state, and harder yet to measure it; yet he who has seen a hopeless child, knows what is not there.

Hope is both the earliest and the most indispensable virtue inherent in the state of being alive. (p. 115)

By referring to hope as a virtue, Erikson believes that hope is an inherent quality of human strength, an essential ingredient to life being sustained. Hope is one of the basic virtues "with which human beings steer themselves and others through life" (Erikson, 1964, p. 115).

Lynch (1965) also asserts that hope begins to grow in childhood, and that it develops out of a trusting relationship between child and caregiver. The child needs something, calls out for help, and receives a response to its need. "A growing sense of the mutual interaction between call and response is part of the growth of hope" (p. 42). The trust and ability to hope established in these first mother-infant interactions enables the child to reach beyond that primary relationship to the world beyond. "The child is full of hope that everything in life, every object, every person, will conform to the security of certain ideal moments spent with a mother acting ideally in terms of his needs. This is the first dream of hope" (Lynch, 1965, p. 58).

While hope is the first and most basic quality of experience, it is also the most lasting. Being part of the life process, hope must be seen as having a maturational component. Erikson (1964) writes that

The gradual widening of the infant's horizon of active experience provides, at each step, verifications so rewarding that they inspire new hopefulness. At the same time, the infant develops a greater capacity for renunciation, together with the ability to transfer disappointed hopes to better prospects; and he learns to dream what is imaginable and to train his expectations on what promises to prove possible. All in all, then, maturing hope not only maintains itself in the face of changed facts - it proves itself able to change facts, even as faith is said to move mountains. (p. 117)

As children experience their world, it appears that they become better able to distinguish between the impossible and the possible, between fantasy based wishes, and hopes (McGee, 1984; Wright & Shontz, 1968). As part of gaining a sense of what is

realistically possible, Lynch (1965) asserts that children experiment with hope and hopelessness (the impossible), in attempts to discover both their powers and limitations.

Hope also becomes more stable through the process of maturation. Children live in the present, and their "attention is consumed by a flash of time - with the inevitable consequence that...hope rises and falls with it" (Lynch, 1965, p. 36). Each fulfilled hope leads to the promise of future hopes, and each failed hope provides energy for the child to seek new hopes (Lynch, 1965). "It is a time of imagination and freedom. A child can be taught to laugh at the lack of hope" (Lynch, 1965, p. 61).

It is evident that the above discussion centers around particular, or specific hopes as held by the child. Erikson (1964) makes clear, however, that "the disposition, to be sure, is for Hope, not for a particular variety of prescribed hopes" (p. 142). He claims that as man matures this disposition will be realized as concrete hopes, or things hoped-for, and will be "quietly superceded" by a more advanced hope (p. 117).

Whether it is the disposition for hope, or the ability to perceive specific hopes, developmental theory establishes that hope is evident from the beginning of life. Despite the fact that children are capable of hoping, and that hope is an essential human virtue, the topic has been virtually ignored in the psychological literature of children.

Hope and Children

As indicated earlier, existing psychological literature which refers to hope and children is scarce. A review of related educational and medical literature is not much more encouraging; a total of three articles referring to hope and children, from rehabilitation, nursing, and pediatric oncology perspectives were published between 1968 and 1994. Four additional articles refer specifically to adolescents, but will also be presented here.

Wright and Shontz (1968) interviewed parents, therapists and teachers of children with such disabilities as spina bifida and cerebral palsy. Fourteen children between the ages of 5 and 19 were also interviewed, regarding their hopes for the future. The authors suggest that hopes are "wishes that might come true" (p. 322), and used interview questions such as "How far in school do you hope he can go?" (p. 323). An analysis of the psychological forces behind interviewee's responses led the

researchers to construct a total of seven hope structures which were ranked developmentally from the young child to the mature adult. Findings suggested that children's hope structures differed from adults' structures in that they lacked an orientation to reality. "The most primitive hopes may be expected to be equivalent to desires that are neither time- nor reality-dependent. With further maturation, the hopes of the young child become future oriented. The reality issue, however, does not enter yet" (p. 324).

While this is the only article which addresses a possible developmental component to hope, it is not particularly helpful. The emphasis of the interview questions appear related to specific hopes, or perhaps even expectations about future goals, rather than aimed at understanding the experience of hope for the parents, teachers and children.

The second article referring to hope in children was published in 1984 by Artinian, who interviewed bone marrow transplant patients between the ages of ten and twenty years. The purpose of her study was to "describe how professional helping relationships assisted parents and children to experience mutual supportive relationships" (p. 57). Evidence of hope was indicated by active planning for future events. Unfortunately, the study lacks adequate explanation of methodology and data analysis, and does not indicate what involvement the children had in the study. There is no presentation of what hope is to children.

Most recently, hope in children has been referred to by Snyder (1993), who is in the process of developing two tools, the Kid Hope Scale (ages 8 - 16) and the Kiddy Hope Scale (ages 4 - 9) in order to measure children's hope. Snyder et al. (1991) developed an adult Hope Scale based on a theoretically derived definition of hope that emphasizes "the individual's desires and the strategies by which those desires are met" (p. 287). "Hope is defined as a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (p. 287).

The child versions of the Hope Scale are based on the same theoretically derived definition of hope, but the language is simplified to be age appropriate (Snyder, 1993). Although Snyder offers suggestions and hypotheses regarding how information gained from these measures of hope may help children, parents and health

professionals, it is unfortunate that neither the definition of hope, nor the individual hope scale items have been derived from the point of view of children.

Hinds (1984), in an article from a nursing perspective, described her use of grounded theory methodology to arrive at an adolescent definition of hope. The adolescents interviewed ranged in age from 13 to 17 years, and included both well individuals and those previously hospitalized for substance abuse. Contained in the semistructured interview were questions such as "What is hope to you?" and "How can you tell a person who is hopeful from one who is not?" (1984, p. 360). Based on this study, hope was defined as "the degree to which an adolescent believes that a personal tomorrow exists" (1984, p. 360).

In 1988, Hinds conducted another grounded theory study with adolescents aged 13 to 18 years, with the aim of clarifying "the concept of hopefulness in the context of health and illness in adolescents" (p. 80), or to "capture the essence of adolescent hopefulness" (p. 87). Using a semi-structured interview with well teenagers, those with a history of substance abuse, and adolescents with cancer, Hinds induced a definition of hope which in its final form reads that hopefulness is "the degree to which an adolescent possesses a comforting or life-sustaining reality-based belief that a positive future exists for self or others" (p. 85).

Hinds (1988) suggests that higher specificity of and more realistic hoped-for objects are indicative of higher levels of adolescent hopefulness. Hence, nurses are encouraged to help adolescents identify specific hopes and then take action to realize them. Of particular interest also, was that adolescents with cancer emphasized the importance of hoping for others, which is similar to information obtained from older adults, but is not consistent with the data obtained from well or substance-abusing adolescents.

Using the adolescent definition of hope, Hinds then constructed a measure of hope entitled "The Hopefulness Scale For Adolescents" (HSA), a "24-item visual analogue scale designed to measure the degree of positive future orientation an adolescent feels at the time of measurement" (Hinds & Gattuso, 1991, p. 93). At present this scale is used primarily by nursing staff with adolescents experiencing cancer.

Hinds' desire to investigate the hope of adolescents is a positive contribution to the study of hope. The interview questions used in Hinds' studies are of interest and assisted me in framing my approach to inquiry with children. However, her presentation of information appears aimed at inducing an operational definition, rather than at sharing the experience of hope from an adolescent perspective. Also, as the subjects used in the studies were adolescents, it would be misleading to generalize the information obtained, or the definition induced, to children.

Following Hinds' construction of "The Hopefulness Scale For Adolescents" (HSA), Saba (1991) used grounded theory methodology to investigate the effects of peer interaction on the hope levels of adolescents with cancer, as measured by the HSA. Results indicated that "subjects with higher peer attachment scores had higher levels of hope" (p. 85). Although I wonder about the use of an assessment tool to measure such a feeling based, intangible concept as hope, this study clearly helps emphasize the increasing awareness of hope as a vital ingredient in the treatment of cancer.

The importance of hope is further established by a study conducted with 38 pediatric cancer patients (Goertzel & Goertzel, 1991) focusing on the role of locus of control, self concept and anxiety in children's health. While the results of the quantitative portion of the study are not related to a discussion of hope, qualitative interviews conducted to explore how the children coped with life threatening illness are most interesting. The majority of children interviewed "said to be hopeful because attitude is the most important thing" (p. 537). "Hopefulness was clearly the most important issue to them" (p. 537). The authors also stress the need for further exploration of hope in relation to pediatric cancer patients.

As the above article suggests, it appears that hoping and coping are in some way related. Although the relationship is not clear, one leading hope researcher suggests that hoping and coping support each other and are considered different but concurrent processes (Nekolaichuk, 1990). Although hoping has been little researched with children, the concept of coping as it pertains to pediatric cancer has been a focus of psychosocial investigation since the 1960s, with over 200 studies being published. For a comprehensive overview of pediatric oncology coping literature, Kupst's recent

book chapter entitled *Coping with pediatric cancer: theoretical and research perspectives* (1994) is most informative.

Coping, by children with cancer, has been characterized as consisting of various tasks that children do in particular situations to help them deal with distress. Different authors and theorists suggest different strategies, but they primarily focus on having a positive outlook and on maintaining good social support through important relationships (Kupst, 1994). Hoping has not been directly referred to in pediatric oncology coping literature, but it is easy to see where there might be room for it, specifically in relation to overall, or global coping styles or abilities.

Hope has been explored with pediatric cancer patients to some degree, and is presented outside the professional literature. Erma Bombeck, in her book entitled *I Want to Grow Hair. I Want to Grow Up. I Want to Go to Boise* (1988) includes a section based on children with cancer and their siblings describing hope to a social worker who had asked what hope would look like if it were an animal. Some responses include:

Hope is about two and a half feet tall.

He is covered with fur and it's fluffy.

It is the color of sunshine and happiness.

Hope raises its voice sometimes. It has to talk louder than fear.

Hope has offsprings like any other animal. They're called Hopelets. You don't keep them. You share them with other people who need one. (p. 142,3)

Children with life threatening illnesses attending Paul Newman's Hole in the Wall Gang Camp were invited to express their feelings through an innovative poetry program one summer. Profiles of five campers and their poetry were published under the title *Where hope grows like the grass*. One camper named Katie wrote of "A field of pinkish-purple hope, growing like love. Each petal is a wish" (Newman, 1992, p. 72).

Although the words are different, less sophisticated, and the images more concrete, who could suggest that these children have any less an understanding of hope, or of the experience of hoping? As we move toward a closer understanding of hope in the lives of others so that we might encourage and possibly enhance that hope, we must remember not only the words of scholars, but the wisdom of children.

III. INQUIRY

*There are two worlds; the world that we can measure with line and rule,
and the world that we feel with our hearts and imagination.*

(Leigh Hunt)

The Research Question

Presentation of the research question will precede a detailed description of the chosen methodology, as it is essential that the approach to inquiry be determined by the research question (Van Manen, 1990). As indicated earlier, the purpose of my research is to explore and present hope from the child's perspective, specifically the child living with cancer. Phrased differently, what is the nature of hope for a child living with cancer?

Choosing an Approach to Inquiry

This study explores children's hope from a qualitative research perspective. Choosing a qualitative approach to understanding hope reveals some basic assumptions about the nature of hope. Hope is a human experience. It is a personal, subjective experience that is not readily measurable. Hope is not "out there" to be counted, or quantified.

Antoine de Saint-Exupery (1943) in his book *The little prince* is trying to introduce to his readers an extraordinary small person whom he meets in his travels:

If I have told you these details about the asteroid (the prince's planet), and made a note of its number for you, it is on account of the grown-ups and their ways. Grown-ups love figures. When you tell them you have made a new friend, they never ask you any questions about essential matters. They never say to you, "What does his voice sound like? What games does he love best? Does he collect butterflies?" Instead they demand: "How old is he? How many brothers has he? How much does he weigh? How much money does his father make?" Only from these figures do they think they have learned anything about him....

But certainly, for us who understand life, figures are a matter of indifference. I should have liked to begin this story in the fashion of the fairytales. I should have liked to say: "Once upon a time there was a little

prince who lived on a planet that was scarcely any bigger than himself, and who had need of a sheep..."

To those who understand life, that would have given a much greater air of truth to my story. (p. 16)

What sort of "air of truth" am I seeking in doing hope research? Rather than searching for a particular, discoverable truth, by using a qualitative approach, I am open to layers of reality and multiple truths as evidenced by experience (Guba, 1990; Guba & Lincoln, 1985). I am searching to understand what experience children have had with hope. What do they think hope is? How do they express it?

Within the realm of qualitative research, there are various methodologies or perspectives from which to choose. Not all qualitative research will serve my purpose for hope research. While the different perspectives vary as to basic assumptions, purpose, and method of data collection, I find myself able to appreciate these variations and see their applicability to certain research questions. It is with regard to methods of data analysis that the differences become striking.

When I look at other research or research examples which appear similar to the type of inquiry I am considering, the data analysis used is commonly some type of content analysis (Guba & Lincoln, 1981; Strauss & Corbin, 1990). Content analysis, with its use of terms and methods such as open coding (breaking down, examining, categorizing), and axial coding (putting data back together by connecting categories), seems contrary to my understanding of hope.

Taking excerpts of people's expression of their experience, such as words or phrases, and analyzing them individually appears to me to decontextualize the expression from the experience as a whole. I found support for this idea in the literature when reading Patton (1990) on qualitative themes. He stresses the need for both context sensitivity and holistic inquiry so that "greater attention can be given to nuance, setting, interdependencies, complexities, idiosyncrasies, and context" (p. 51).

If, for example, I were to collect stories of hope from three children, and then proceed to cut their sentences into strips, label them and place them in piles according to concepts and categories in preparation for later systematizing and solidifying of connections (Strauss & Corbin, 1990), I would feel very removed from the individual experiences of hope. Perhaps it is the language of content analysis which I find

inappropriate in relation to hope inquiry. Phrases such as "objective coding" and "breaking down" seem insensitive to a hope experience, and removed from the words people use to talk about their own hope experiences.

To take people's expressions of their experience of a phenomenon, and label them with words apparently borrowed from a scientific paradigm, may allow us to better categorize or organize the data, but I question whether it brings us toward a better understanding of the experience. Perhaps individuals' expressions are not orderly and neat, but might that also tell us something of their experience? For a child to choose a particular method of expressing hope, is to say both something about hope and about the child. I feel we must stay as close to individuals' expressions as possible, as close to their lived experience as we are able, in order to move toward a deeper understanding of that experience.

For me to research hope, and feel that I am being sensitive and true to the phenomenon under exploration, I need a methodology whose language is congruent with a language of hope. Language for hope, especially in the research literature, is limited. Perhaps in an attempt to overcome that limitation, researchers are using terms such as "hope object", "hope deficit condition", and are borrowing language from the scientific community in order to express aspects of hope. I wish to present children's ideas from their perspective, and then move toward some form of interpretation of what their expressions might tell us about the nature of their hope experience.

To access and attempt to understand people's hope, we must let it come from them, from their experience, from their lives. How then do I invite others, specifically children, to share their hope with me?

Approach to Inquiry

The specific approach to inquiry which fits most closely with the exploration of children's hope is hermeneutic phenomenology, as explicated by Van Manen (1990) in Researching lived experience: Human science for an action sensitive pedagogy. While this is the major guide for my writing, I have also been influenced by Moustakas' (1990) Heuristic research: Design, methodology, and applications, and utilize his insights where applicable.

"Hermeneutic phenomenological research is a search for the fullness of living" (Van Manen, 1990, p. 12).

It is the phenomenological and hermeneutical study of human existence: phenomenology because it is the descriptive study of lived experience (phenomena) in the attempt to enrich lived experience by mining its meaning; hermeneutics because it is the interpretive study of the expressions and objectifications (texts) of lived experience in the attempt to determine the meaning embodied in them. (p. 38)

Through a process of thoughtful reflection and writing, phenomenology seeks to "*construct a possible interpretation of the nature of a certain human experience*" (Van Manen, 1990, p. 41). In my research, I explored hope with children, and present a possible interpretation of the nature of their hope. The interpretation is based on the expressions children provided during the hope exploration. As Van Manen (1990) remarks, "phenomenology is, on the one hand, description of lived-through quality of lived experience, and on the other hand, description of the meaning *of the expressions of lived experience*" (p. 25).

While hermeneutic phenomenology does not have a prescribed set of investigative rules, there are certain methodological themes and features based on a tradition of great thinkers and writers who comprise the history of phenomenology. "Thus the broad field of phenomenological scholarship can be considered as a set of guides and recommendations for a principled form of inquiry that neither simply rejects or ignores tradition, nor slavishly follows or kneels in front of it" (Van Manen, 1990, p. 30).

The guides outlined by Van Manen (1990), intended to "animate inventiveness and stimulate insight" (p. 30), are a framework for inquiry, while providing freedom and promoting creativity on the part of the researcher. The six research endeavors are as follows:

- 1) turning to a phenomenon which seriously interests us and commits us to the world;
- 2) investigating experience as we live it rather than as we conceptualize it;
- 3) reflecting on the essential themes which characterize the phenomenon;
- 4) describing the phenomenon through the art of writing and rewriting;

- 5) maintaining a strong and oriented pedagogical relation to the phenomenon;
- 6) balancing the research context by considering parts and whole. (p. 30)

Moustakas' (1990) heuristic research involves many of these same activities, but also requires in depth personal experience of the phenomenon. Although I admire his methods and commitment to the phenomena about which he writes, I do not see my personal experience of hope to be critical enough to this study to fulfill his definition of heuristic research. Despite this, however, some of his writing has influenced my approach to inquiry. Moustakas (1990) contrasts heuristic research with phenomenology (p. 38). Interestingly, many of the distinctions he feels are specific to heuristics, are closely aligned with hermeneutic phenomenology. Moustakas (1990) does, however, explicate one notion which is perhaps only implicitly evident in Van Manen's writing - the importance of the individual person.

While phenomenology upholds a "theory of the unique" (Van Manen, 1990) wherein the uniqueness of individual persons is valued, heuristic research goes further. Heuristics focuses on the whole person throughout the research process. Rather than searching for the essence of the experience, heuristics searches for the essence of the experiencing person. "The focus in a heuristic quest is on recreation of the lived experience; full and complete depictions of the experience from the frame of reference of the experiencing person" (Moustakas, 1990, p. 39).

To obtain such full and complete depictions, phenomenology and heuristics both emphasize researcher ingenuity.

Every method or procedure, however, must relate back to the question and facilitate collection of data that will disclose the nature, meaning, and essence of the phenomenon being investigated. This means methods and procedures that will yield accurate and vivid dimensions of the experience - situations, events, relationships, places, times, episodes, conversations, issues, feelings, thoughts, perceptions, sense qualities, understandings, and judgments. (Moustakas, 1990, p. 44)

Any ethically responsible modes of inquiry that the researcher feels will yield such rich information are considered appropriate. Given the nature of human science research, these modes or techniques of inquiry may not always be specified in advance (Guba & Lincoln, 1985). A sense of openness and ambiguity must be tolerated which "allows

for choosing directions and exploring techniques, procedures and sources that are not always foreseeable at the outset of a research project" (Van Manen, 1990, p. 162).

Techniques of Inquiry

Inquiry in phenomenology may be considered an art form; the researcher is free to create techniques designed to gather experiential material. Modes of inquiry are sought which will "explicate meanings and patterns of experience relevant to the question, procedures that will encourage open discussion and dialogue" (Moustakas, 1990, p. 44). How then do I invite the children to share their hope with me? How do we embark on our exploration of the nature of hope?

Simply asking children to tell me what hope means won't likely uncover any more than reiterations of the words they hear adults using to talk about this "thing" called hope. That is not the information I wanted to explore. Instead, I wished to access the lived meaning of hope; not what the children "know", but what they sense, what they understand, what they experience.

As with every other human experience, words are insufficient to describe the experience. In fact, most of the time words do the opposite: they obscure it, dissect it, and kill it. Too often, in the process of talking about love or hate or hope, one loses contact with what one was supposed to be talking about. Poetry, music, and other forms of art are by far the best-suited media for describing human experience because they are precise and avoid the abstraction and vagueness of worn-out coins which are taken for adequate representations of human experience. (Fromm, 1968, p.11)

Polkinghorne (1983) summarizes Wilhelm Dilthey's earlier views, writing that "the most substantial sources of knowledge about the life experience are the expressions of life - for example, the pictures painted, the letters written, the poems and stories composed, and the institutions created" (p.32).

I invited children to explore hope through drawing, painting, pictures, or story, as well as through dialogue or interview. Experience with children in educational and therapeutic situations has taught me to initially encourage children to express themselves nonverbally. Once children become engaged in a nonthreatening, enjoyable activity, they are more likely to express their thoughts, feelings and experiences

verbally as well. Used together in an interactive way, art and dialogue can provide rich information about children's worlds.

Levick (1986), writing on the nature of children's drawings, notes that "anything created by someone - a drawing, a painting, a piece of sculpture - is a nonverbal message from the creator about the inner self and that artist's world" (p. 29). She goes further to say that

If we can begin to understand how the artist, through the creative process, transforms personal chaotic feelings and ideas into order, we can begin to understand how children naturally use drawings to organize the multitude of new experiences they encounter as they grow and create a sense of balance within themselves. (Levick, 1986, p. 33)

Using their nonverbal expressions of hope as a starting point, I then encouraged the children to enter into dialogue with me about their expressions. Interpreted in concert, verbal and nonverbal expressions may lead to a more complete understanding of the nature of children's hope.

Interview or dialogue in phenomenological research is used for the specific purpose of "exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon" (Van Manen, 1990, p. 66). To achieve this purpose, the researcher must remember that the human phenomenon under exploration is always at the heart of the interview; one needs always to be oriented to the question that initially prompted the interview.

While Van Manen (1990) uses the term conversational interview, Moustakas (1990) prefers dialogue, saying that it "aims toward encouraging expression, elucidation, and disclosure of the experience being investigated" (p. 47). I conducted two, one hour audio taped interviews with each of the children, which, while following a general set of possible inquiry techniques and questions, were spontaneous and allowed the children to freely express themselves. Below is a sample of techniques I had compiled prior to beginning the interviews. Based on the interviews with individual children, new questions and approaches were added as needed. "Although general questions may be formulated in advance, genuine dialogue cannot be planned" (Moustakas, 1990, p. 47).

Possible Interview Techniques

- 1) Describing or drawing a picture of hope. What does hope look like? Is it an animal, a person, or a place? Where is it? What color is it? How big, or small - what size is it?
- 2) A kid from another planet comes to visit you. She doesn't know what hope is, they don't have any on her planet. How would you explain it to her?
- 3) A friend of yours needs some hope - and you want to help him. You want to give your friend a "hope kit" (R. Jevne, personal communication, May 4, 1993). What would you put in the kit? What would you leave out of the kit? When would you give it to your friend?
- 4) Think about someone who you feel is really hopeful. Tell me about that person. How can you tell that person is hopeful?
- 5) Sometimes hoping is hard. Tell about a time in your life when it was hard for you to hope. What made it hard? Who, or what got in the way of your hope? What helped? How did you hope even when it was hard?
- 6) Tell me about your hope. What does it mean to you? Where do you get it? Do you always have the same amount? Who helps you with your hope? Can you share it? How? With whom?

In addition to gathering material by combining children's verbal and nonverbal expressions of hope, I also made use of what Van Manen (1990) refers to as close observation. Close observation requires the researcher to become as much a part of the life world of the participant as possible, while still maintaining a "hermeneutic alertness" (p. 69) which allows the researcher to reflect on the meaning of what is experienced or observed. As an additional source of information, and based on my observations, I recorded personal reflections after each child interview, and kept notes and memos throughout the data collection phase.

Research Participants

The children who explored hope with me are pediatric patients of a regional cancer treatment hospital. My reasons for choosing children living with cancer were threefold. In order to explore hope from the perspective of children, I wanted to access children who would appear to have high need for hope in their lives. As Marcel

(1951/65) suggests, only when there is a threat or challenge to hope, can it really be present. Secondly, there are requests in the pediatric oncology literature for further research on hope from the perspective of children (Bernheimer, 1986; Goertzel & Goertzel, 1991).

Finally, I have the opportunity and pleasure of working with children living with cancer in my position as a psychologist. I enter these children's lives through therapy, and am allowed to spend time seeing the world through their eyes. I chose to explore hope with these children so that I might reflect on how "we should talk and act with them and how we should live by their side" (Van Manen, 1990, p. 139).

Gathering information about hope from children living with cancer is an example of the purposeful sampling advocated by qualitative inquiry (Morse, 1994; Patton, 1990). Purposeful sampling, seeking information rich cases to be studied in depth, rather than a representative sample, has "no rules for sample size" (Patton, 1990, p. 184). The number of participants is ultimately determined by the quality of information that emerges through the inquiry process. "In qualitative research, the investigator samples until repetition from multiple sources is obtained. This provides concurring and confirming data, and ensures saturation" (Morse, 1994, p. 230). In obtaining saturation in this study, I explored hope with the children until themes began to repeat themselves, and the children had no new information to add.

The relationship between researcher and participant is also an important consideration in qualitative research. By exploring hope with children I was involved in an interactive process, and entered into a "complementary relationship" (Guba & Lincoln, 1981, p. 143) with the children. Essential to this relationship is not the objectivity of a quantitative researcher, but rather sensitivity and empathic understanding.

The Explorers

I explored hope with four children between the ages of six and nine: Tyler (6), Curtis (8), Jessie (8) and Michael (9). (Their names have been changed to preserve the privacy of the children and their families.) All four of the children have experienced cancer and have been both inpatients and outpatients of the cancer centre.

Additional demographic information is essential to providing the reader with a context for this hope research. Tyler, Curtis, Jessie and Michael were caucasian children from intact, two parent families living in or around a metropolitan centre. The families were financially stable, with one or both parents having post secondary education and established careers. Each of the children had either one or two siblings also living at home. Some sense of spirituality was given to each of the children by their family, although not necessarily in the form of a prescribed religiosity. The four children were similar with regard to family, culture and socioeconomic status.

The children chosen for this study were between the ages of 6 and 9, although the possible age range was from ages 6 to 12. I specified this age range, as children in this group are capable of concrete operational thought, and have a fairly good grasp of time frames. These children are able to understand the seriousness of their illness and begin to understand that death is permanent and nonreversible (Rowland, 1989, p. 527). As mentioned earlier, these are important concepts which may relate to various aspects of hope.

Tyler and Curtis became co-explorers with me after I had been seeing them for therapy for some time. Jessie and Michael were referred to me as potential explorers after being told about the hope study by a nurse coordinator during an outpatient visit. More detailed descriptions of the children follow in Chapter IV where their individual stories are told.

The consent form explaining the study to the children's parents is included in Appendix A, and the cover letter provided to parents by the nursing coordinator is shown in Appendix B. An interview guide (Appendix C) and demographic data sheet (Appendix D) were shown to the children's pediatric oncology team as part of obtaining the team's permission for the children to participate.

Thoughtful Reflection: Thematic Analysis

"Every human expression means more than it can say" (Erikson, 1977, p. 41). Using different modes of expression as sources of data requires the researcher to have some knowledge or theory on the nature of expression. How do the expressions give meaning to the experience of the individual? How can the researcher best interpret the

expressions, while at the same time staying true to the individual's personal experience of hope?

In order to determine the most appropriate method of analyzing the data, the research question and goals of the research must be closely examined. According to Miller and Crabtree (1994),

the goal of exploration, the absence of significant literature about the question, and the use of interviews argue for a style that is unstructured, fosters intimate contact with the text, and minimizes perceptual filtering in the initial analysis....An immersion/crystallization style or a very open editing style (such as hermeneutics)...is thus appropriate. (p. 347)

As the research aims to explore hope, the literature regarding hope and children is limited, and our explorations involved indepth interviews, the above considerations fit well with this study.

A combination of the thematic analysis used by Moustakas (1990) and Van Manen (1990) is the type of qualitative analysis which is most effective given data sources such as art, and story. Through reflective interpretation, I illuminated the experiential material gathered to help the children share their hope experience with others.

Moustakas' (1990) heuristics encourages a gentler, more holistic approach to analysis than other qualitative methods I have encountered. He suggests leaving individual cases intact, and exploring themes that emerge from the individuals' expressions. Only after individual depictions are formed, does the researcher begin to combine the various case depictions in search of larger trends. "The composite depiction...includes exemplary narratives, descriptive accounts, conversations, illustrations, and verbatim excerpts that accentuate the flow, spirit, and life inherent in the experience. It should be vivid, accurate, alive, and clear, and encompass the core qualities and themes inherent in the experience" (Moustakas, 1990, p. 52).

Van Manen (1990) appears to agree, when he asserts that "too often theme analysis is understood as an unambiguous and fairly mechanical application of some frequency count or coding of selected terms in transcripts or texts" (p. 78). Because phenomenology is description of human experience, and is seeking meaning, such break-down and decontextualization of material can be misleading. Rather, Van Manen

(1990) suggests that "making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure - grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning" (p. 79).

Themes in hermeneutic phenomenology are simplifications, or attempts at organizing, capturing, and structuring experience. By identifying themes, the researcher is striving to better understand, or make sense of the experiential material. Themes are generally uncovered from text by examining the text as a whole, by selecting specific or essential phrases, or by examining the text line by line. Once themes are identified, they then become objects for further reflection by the researcher (Van Manen, 1990).

Analyzing the Explorations

Miller and Crabtree (1994) suggest that all qualitative analysis must address three basic steps: "developing an organizing system, segmenting the data, and making connections" (p. 345). Further, they have divided qualitative analysis into four types, one of which is immersion/crystallization, mentioned earlier, where the three steps "are collapsed into an extended period of intuition-rich immersion within the text" (p. 345). This method is based largely on the work of Moustakas (1990) and fits well with my hope exploration.

As "it is the interpreter, as an editor, who serves as the organizing system" (Miller & Crabtree, 1990, p. 345), it is essential that I make clear the activities I followed in analyzing the children's hope explorations. After each individual interview with a child, I personally transcribed the audio tapes into text. I did the transcribing myself in order to immerse myself in the words, sounds and silences of the children talking about hope. Also, because it is often difficult to truly capture what children have said on tape unless one is familiar with their speech, I thought it best that I did the transcribing myself, while the interviews were still fresh in my mind and to my ears in order to insure accuracy and clarity. Once I had transcribed the interviews, I verified each text by reading it as I listened again to the tape recording.

In the initial stages of analysis I maintained each child's interview as a whole. I read each interview from beginning to end several times, allowing myself time to

contemplate and revisit the text to gain a better understanding of what the children were saying. I wanted to make sure that I captured the nuance and meaning that was imbedded both in the text and in the children's images. I then began line by line readings to identify preliminary themes for each child. I also looked for discrepancies or ideas which might need clarification during the second interview.

Once preliminary individual themes were identified, I began to compare the themes, words and pictures among the four children, again looking for confirmation and discrepancy. During second interviews I also asked the children to comment on ideas set forth by the others, and to tell me how they might see things the same or differently than other children. After weeks of immersion, thinking, rethinking and returning to the data, a variety of themes were solidified and became the basis for a creative synthesis of the data, which then led to the writing of chapters four and five.

Presentation: The Art of Writing

"In phenomenological human science, writing does not merely enter the research process as a final step or stage;...human science research *is* a form of writing" (Van Manen, 1990, p. 111). Thoughtful, reflective writing and rewriting is central to phenomenology. The interpretations made, and the themes identified from the experiential data must be meaningfully conveyed in text. To simply present transcripts and let the data speak for themselves, is to fall short of the "interpretive and narrative task" (Van Manen, 1990, p. 167) of hermeneutic phenomenology.

According to Van Manen (1990),

to present research by way of a reflective text is not to present findings, but to do a reading (as a poet would) of a text that shows what it teaches....In the work of writing and reading a text we must always ask: how can we invent in the text a certain space, a perspective wherein the pedagogic voice which speaks for the child can let itself be heard? (p. 153)

As an ideal for sharing the children's voices, I hope also to attain in my writing some of the following aspects of Moustakas' (1990) final step in heuristic presentation:

- development of a creative synthesis of the experience
- a wide range of freedom in characterizing the phenomenon

- the researcher as scientist-artist develops an artistic rendition of the themes and essential meanings of the phenomenon
- presenting the discovery of essences - peaks and valleys, highlights and horizons.

In the creative synthesis, there is a free reign of thought and feeling that supports the researcher's knowledge, passion, and presence; this infuses the work with a personal, professional, and literary value that can be expressed through a narrative, story, poem, work of art, metaphor, analogy or tale. (p. 52)

Integrating aspects of both hermeneutic phenomenology and heuristics allows for a presentation that fits well with hope. It does not break the experience of hope apart, nor change its language; such a presentation allows children and hope to speak of themselves.

Trustworthiness

Whatever the specific techniques of inquiry and presentation, human science research must be trustworthy, a quality achieved by maintaining, throughout research, a sense of rigor. In contrast to quantitative research, where rigor requires adherence to exact procedures, objectivity, and removal of error, phenomenological research speaks of rigor in a "moral and spirited sense". By "its courage and resolve to stand up for the uniqueness and significance of the notion to which it has dedicated itself", human science research "is prepared to be soft, soulful, subtle, and sensitive in its effort to bring the range of meanings of life's phenomena to our reflective awareness" (Van Manen, 1990, p. 18).

After extensive reading in the area of trustworthiness and judging the goodness of qualitative research, I decided to ensure that this study can adequately speak to the following questions, which I developed after reading Miller and Crabtree (1994).

1. Is the researcher credible and qualified?
2. How believable is the text?
3. How was the research designed and done?
4. Does the research make clinical sense?

By referring to leading experts in the field of trustworthiness, and recounting my research endeavors, I will address these four issues here, as well as the strategies used to enhance trustworthiness in each of the areas.

Is The Researcher Credible and Qualified?

In contrast to quantitative research, where researchers use tools or instruments for inquiry, the researcher is the primary instrument in qualitative research (Guba & Lincoln, 1985).

Because qualitative inquiry depends, at every stage, on the skills, training, insights, and capabilities of the researcher, qualitative analysis ultimately depends on the analytical intellect and style of the analyst. The human factor is the great strength and the fundamental weakness of qualitative inquiry and analysis. (Patton, 1990, p. 372)

I must, therefore, be able to present my personal approach to exploring hope with children, and articulate my clinical and research experience so that the reader may judge my credibility as a qualitative researcher conducting research with children.

Approaching the exploration of hope with children

As far back as I can remember, I have been drawn to children who are challenged in some way. In elementary school I recall wondering about my classmates who were having trouble reading, or learning to divide. Those tasks were always so simple for me, and new learning came easily. I didn't wonder so much about why the others had trouble, instead trying to imagine how they might be feeling. How could they come to school day after day when everything was so hard for them?

For grade ten work experience, I chose to spend time in an elementary special education class, and was again struck by the courage and perseverance of the little children who struggled so hard both with physical and academic limitations.

Part way through my University degree in special education, I began volunteering at Sunny Hill Hospital with children who were severely dependent handicapped. It was a new and scary experience for me. It took several weeks before I could look past the wheelchairs, feeding tubes and braces to see the children. Looking back at a journal I kept at the time I have found a line I wrote in relation to

finally seeing the children. "I see the children of Sunny Hill - their hope, their fears, tears, laughter, trials, successes and their smiles!" Their hope comes first. I wrote that in 1988, years before I even considered researching hope in children, yet somehow I knew that it was important, and was a large part of my work with children.

I am now a psychologist working with children on an oncology ward. The challenges for the children are different than those of a child having trouble in school, or one who can't walk or speak, but the courage, the presence and the determination is similar. I choose to call it hope, and I believe that it helps sustain the children and make their struggles easier. I wanted to know if the children think of it that way too, so I asked them to explore hope with me.

Research and clinical experience

I have had theoretical, teaching and practical experience in both qualitative and quantitative research throughout my master and doctoral level training. While both approaches are valuable, their value is specific to the type of information being sought. Given that I wanted to explore the experience of hope with children, I determined that qualitative inquiry best suited the topic. Qualitative research also fits most closely with the clinical work I do and the way I am with children.

Throughout my training I have had considerable experience working with children in clinical settings, doing both assessment and counselling work. The clinical skills I have developed and enhanced which are relevant to this research include rapport building, empathic listening, creative and open questioning, and careful observation. I also take care to respect children and to treat them in a manner which encourages and supports them. Finally, I try to make children's interactions with me enjoyable for us both. Together we laugh and play and look for the good in life and in ourselves.

How Believable Is The Text?

Truth value is an essential element of any rigorous research. Referred to in quantitative research as internal validity, truth value has its parallel in qualitative research in credibility (Guba & Lincoln, 1981). Credibility of phenomenological research is a question of meaning (Guba, 1990). Does the research, after thoughtful

reflection and presentation, "comprehensively, vividly, and accurately" (Moustakas, 1990, p. 32) convey the essential meaning of the experience?

A primary method of enhancing credibility in phenomenology is by continually returning to the data, texts, or expressions generated by the participants. The researcher must constantly and repeatedly verify interpretations of the data with new and emerging information (Sandelowski, 1986). "Certain visions of the truth, having made their appearance, continue to gain strength both by further reflection and additional evidence. These are the claims which may be accepted as final by the investigator and for which he may assume responsibility by communicating them in print" (Polyani, 1969, p. 30). The ultimate judge of truth value is the researcher (Moustakas, 1990; Van Manen, 1990), although verification may be gained by returning to research participants throughout the interpretive stages.

Throughout this research, I remained in close contact with the data provided by the children. During analysis I returned again and again to the data for confirmation of my interpretations, and for verification of themes. Verification and clarification were also gained from the children, to whom I took the data from the first interviews.

To enhance the credibility of the text to the readers, I took care in the presentation of the data to include evidence from raw data such as direct quotes, reproductions of the children's art work, and examples of interview conversations. The language and style used to present the children's expressions is intended to avoid jargon and to be simple and familiar to the reader, as well as true to the voices of the children.

Van Manen (1990) also writes of a validating circle of inquiry, whereby "*a good phenomenological description is collected by lived experience and recollects lived experience - is validated by lived experience and it validates lived experience*" (p. 27). The reflectively written text, drawn from lived experience, resonates with the lives of others. The interpretation provided of the lived experience is seen as a possible interpretation of the expressions gathered. Guba and Lincoln (1985) refer to this resonance in qualitative research as fittingness.

How Was The Research Designed and Done?

In addition to fittingness and credibility, phenomenological research must be able to demonstrate consistency. While consistency or repeatability in the quantitative realm is referred to as reliability, the accepted qualitative term is auditability. Auditability is evident when the decision making trail followed by the researcher throughout the study is clearly documented for the reader, allowing the reader to review the reasoning process (Guba & Lincoln, 1985; Sandelowski, 1986).

To enhance auditability, I made sure to clearly articulate the rationale leading me to choose qualitative inquiry (see the section entitled Choosing an Approach To Inquiry). Throughout the research process, I kept careful documentation of research activities and have compiled an Audit Trail (see Appendix E) which allows the reader to follow this hope exploration from genesis to completion.

Does The Study Make Clinical Sense?

In order to make clinical sense, the research question and the research itself must matter to the participants, and the information presented as a result of the research should address the applicability to the participants (Miller & Crabtree, 1994). I believe, and the children confirmed, that hope is essential to children living with cancer. During the entire research process, I maintained that the children were the primary reason for conducting this research. In presenting the data, I specifically addressed issues related to working and being with children, and how we might use the findings of this research to help the children and to further research in this area. Presenting information which leads to further investigation is also important to clinically sensible research.

Part of the clinical sense of research is the degree to which the information is useful to the reader in his or her own work with individuals similar to the participants, which is also referred to as transferability. Given my thorough descriptions of the children, and the various aspects of the research process, it is left to the reader to determine the degree of applicability this research may have in other settings. In so determining, please remember that

qualitative clinical research is convincing if the methods are appropriate for the question and the investigator's relationships with informants, data and audience

are clearly addressed; if the audience recognizes itself in the findings; and if the question and results matter to clinical participants. (Miller and Crabtree, 1994, p. 349)

Ethical Considerations

Concern for the well-being of participants is paramount in qualitative research, and special care must be taken when the participants are children. Ethical concerns traditionally center around three basic ethical principles: informed consent, right to privacy, and protection from harm. Prior to conducting this research, I obtained approval from the University of Alberta Research and Ethics Committee in the Department of Educational Psychology, and from the Research Ethics Committee at the regional cancer hospital.

Informed consent was addressed in various ways. I personally explained the study to the children in words appropriate to their level of understanding and answered any questions they had. Prior to beginning the interviews, I obtained verbal consent from the children, and reminded them that we could stop the interview any time they wanted. Informed written consent was obtained from each child's mother, according to the guidelines detailed by the consent form in Appendix A.

Right to privacy was maintained throughout the research process. Pseudonyms were used on written material, and maintained throughout this document. Any identifying statements or references have also been removed. Confidentiality issues were explained to the children and their mothers, and care has been taken throughout the research process to insure confidentiality in communication of any kind.

Protection from harm is relevant to this study because emotional reactions by the children were possible given the nature of the topic and the possible discussion of their illness. As a psychologist trained in work with children, I was able to monitor the emotional responses of the children during the interviews and was ready to intervene with appropriate counselling techniques when necessary. Parents were also aware that if their child experienced any negative reactions after the interviews, professional counselling was available through the Department of Psychology. I am pleased to report that the children expressed no difficulties during or after the interviews.

Delimitations

In developing this research study, I set out certain boundaries or delimitations which require specification. This hope exploration focuses on children, between the ages of 6 and 12, who experienced some form of cancer. They were from fairly homogenous familial and cultural backgrounds and were treated by the same oncology team. To access rich and detailed experiential information, I intentionally chose to explore hope with a small number of children, and to use a hermeneutic phenomenological methodology. I purposefully delimited certain characteristics of the explorers (age, experience with a particular disease), sample size, methodology and form of presentation.

Limitations

As a result of the boundaries I established, I recognize that this study necessarily has its limits. The information I present about hope from the point of view of children, comes from the four children who explored hope with me. Although it might be tempting, I am not only unwilling, but also unable to make generalizations beyond these four children to others who may differ contextually by culture, religion, family, age, and medical or personal history.

Toward The Explorations

As you approach chapters four and five, which reveal the explorations of the children, and my interpretation of those explorations, I ask that you read with these words in mind.

The proof for you is in the things I have made - how they look to your mind's eye, whether they satisfy your sense of style and craftsmanship, whether you believe them, and whether they appeal to your heart. (Sandelowski, 1994, p. 61)

IV. HOPE EXPLORATIONS

Without hope it is like living in a dungeon with no windows. With hope it is like living in a house with 300 windows.

(Sarah Jean Kovar, age 11)

This chapter presents the hope of four children living with cancer: Tyler, Jessie, Curtis and Michael. Like Sarah, they know what it is like without hope, and have chosen instead to live with windows. Through their pictures and conversations with me, the children have allowed the curtains on their windows to be pulled back, so that we might look inside to learn what it is like for them to live with hope. The children's words are presented verbatim in order to provide the reader with the true flavor of the children's voices - their repetitions, hesitancies and idiosyncracies. Minute editing is indicated by ellipses, where some portion of the interview was not included, for reasons of clarity.

TYLER

Meeting Tyler

As I sat at my desk waiting for him to arrive for his first appointment with me, I heard the shuffle and clomp of winter boots on small running legs, and I knew that Tyler had arrived. And that set the stage for all further arrivals - I heard him before I saw him, and he was almost always running.

When I first saw Tyler on that afternoon in January 1994, I noticed his head - not just because it was completely bald, but because it seemed large on his small 5 year old body, and was round and very smooth. I had to resist the temptation to reach out and gently rub the top of his head when I said hello. I am glad I resisted, because as I got to know Tyler, it became clear that he would not have appreciated my rubbing his head. When I got down to Tyler's level so we could meet face to face, I knew I would never notice his head first again, as the mischievous sparkle in his eye and his engaging smile shone much more brightly.

"I Hate My IV Pole"

Tyler Living With Cancer

In July 1993, just two months before the beginning of kindergarten, a tumor was found behind Tyler's right eye, and he was diagnosed with a type of cancer called rhabdomyosarcoma. He immediately received emergency radiation treatments to save his optic nerve, and had a central line catheter (broviac) surgically inserted into his chest so he could begin 11 months of chemotherapy treatment. Tyler finished chemotherapy in May 1994, and his cancer is currently in remission. Those are the medical facts of Tyler's cancer, but they do not begin to reveal what the experience was like for Tyler or his family.

For Tyler, having cancer meant not being allowed to go swimming (because of his broviac), missing kindergarten when he was in the hospital, and having to be "hooked up" via his broviac to his dreaded intravenous pole. It meant being bald and having people stare at him because he looked different. Cancer treatment required Tyler to attend weekly outpatient clinics which meant 8:30 a.m. appointments for finger pokes to check his blood counts, waiting for the results, waiting to see the doctor, and then, if his counts were high enough, being admitted to the hospital to be hooked up for several days of chemotherapy. If his counts were low, he would go home and start the process again the next week.

Cancer got in the way of what Tyler wanted to do, and was therefore something to be gotten around. He had to spend countless hours waiting in clinics...but he could wait in the playroom! Finger pokes hurt...but they were followed by cool plastic rings, and cartoon band-aids. He hated his IV pole...but quickly turned it into a speedy scooter for sailing around the inpatient ward when the nurses weren't looking. (See Figures 1 and 2.) Tyler ignored his cancer whenever possible, yet he faced it head on when necessary.



Figure 1. Try not to cry when you get a needle!

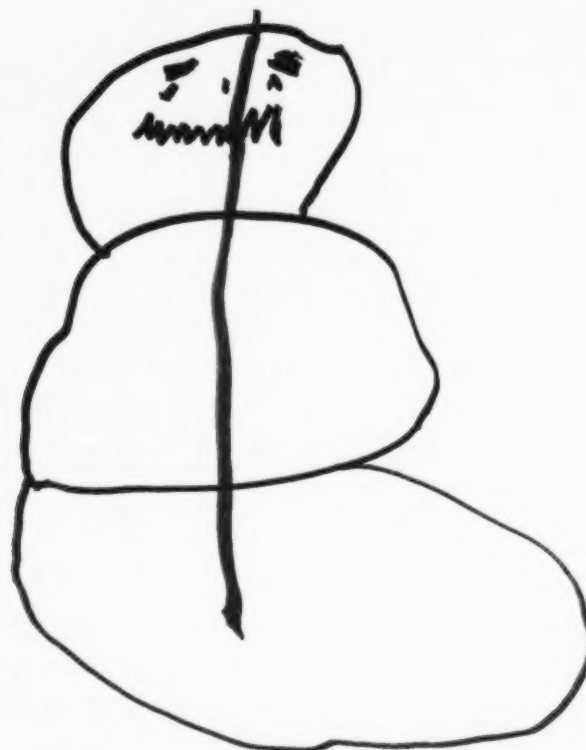


Figure 2. I hate my I.V. pole!

Tyler talked about his cancer with an understanding that surpassed what some children three times his age could muster. He didn't say he was sick, or that he had a "boo boo" as other 5 year olds might. When asked why he had to be in the hospital, Tyler would respond "because I have rhabdomyosarcoma and I need chemo". He knew about tumors and white blood cells and platelets, and he knew that this was all serious stuff. Figure 3 is a picture Tyler painted to show what the tumor in his eye looked like when he first got cancer, and then what it looked like after he had been on chemotherapy for several months. While the first picture of his eye shows a large tumor (in purple), the second eye has only speckles of tumor left.

Despite having cancer and undergoing intensive treatment, Tyler was rarely sick. He embraced life wherever he was, playing, laughing, yelling and having fun. Mothers of children who roomed with Tyler in the hospital often remarked at his presence and courage. They said that his valiant, spirited approach to his illness inspired them and gave them hope for their own children.

I HAVE CANCER



-my eye with
the tumor



-my eye
after chemo

Figure 3. Tyler's eye before and after chemotherapy.



Figure 4. Happy things for Tyler.

During one of Tyler's inpatient admissions, we talked of what kept him going in hospital. To explain, Tyler drew a large yellow sun and filled it with the things that kept him hoping. (See Figure 4.) Tyler drew himself smiling, without cancer or his broviac tube. The two small blue squares represent the procedure that the nurses do to Tyler's broviac before he can go home. He also showed himself leaving the hospital

with his dad to go home, and drew his school building, which reminded him of going back to Kindergarten in a few days.

Although he was brave and determined, there were times when Tyler hated his cancer, and raged at the disease that took away his hair, and his swimming privileges, and at the treatment that interfered with his normal growth pattern, meaning to Tyler that "my baby teeth will take longer to fall out than all my friends'". Tyler was referred to me when he began exhibiting episodes of anger, which he called "mad attacks".

Together Tyler and I played and talked of what it is like to have cancer - the good things and the bad things. I never witnessed a mad attack, and according to his mother they resolved quite quickly, yet Tyler and I continued to talk and play every two weeks. Together we celebrated his one hundredth day of kindergarten, his last chemo treatment, and finally the removal of his broviac! Tyler told his family and his teacher that I was his friend. He is a wonderful, insightful, informed little person. He is definitely my picture of a free spirit.

Exploring Hope With Tyler

When I initially approached Tyler's mother about this study, she consented before I even had the whole title out of my mouth. "Yes, that would be perfect for Tyler, hope is what has gotten our family through this year". Tyler, on the other hand, was not so enthused. Tyler adamantly said he did not want to help me with my project - he had nothing to say and didn't even want to try. He did agree to think about it though. Two weeks later Tyler said he still didn't know what to say, but reluctantly agreed to try.

Tyler arrived at that appointment blowing heartily into a brand new harmonica which he had just bought for seven dollars of his own money. As always, he arrived well ahead of his mother, having left her to register at the main desk. I had seen Tyler earlier that day as he had waved to me wildly when he spotted me next to him in early morning traffic. We rolled down our windows and Tyler yelled to me "Susan, I'm coming to see you at one, I hope you have good stuff to do today!" Once we were inside my office, I asked Tyler to paint a hope picture, and with only a momentary pause he eagerly began painting - our exploration had begun.

Tyler's Hope Picture



Figure 5. Please people that cut down trees,
please replace them please please please.

While he was painting, Tyler explained that he was making a forest that "has lots of trees, some big, some small" and said that the trees "remind me of hope, and the animals that live in them...I'm hoping that the trees won't get cut down, for all the animals that are living in them". He painted "a squirrel running up the tree and a bird's nest", and said that he felt "good" when he looked at his picture, because it reminded him of "the cute little animals" that live in his hope forest. Tyler titled his picture "Please people that cut down trees, please replace them please please please".

Tyler's Hope

As Tyler had so easily produced a hope image, I encouraged him to describe his hope to me in terms of color, shape, size and where it might be. Hope for Tyler "is any color you think it is", but for that day his hope was his favorite color purple which

reminds him of the plums he loves to eat. Although Tyler answered specific questions about hope, indicating that it is "humongous" and "all over the place in your body", and that he gets it from God, he did not elaborate. It seemed as if my questions about seeing or imagining hope did not reach what he was thinking.

Instead, I asked Tyler how he would explain hope to a child from another planet who didn't know what it was. After admonishing me that "no people live on other planets, most of them are gas and some of them are really hot", Tyler agreed to pretend and responded with "I would say that hope is sorta like, if you don't want people to die or anything, just, that's your hope...it's just hope, like wishing". He mentioned wishing for a hundred dollars, hoping for money and "booting his sister out the door" all in the same breath, but upon further questioning decided that these wishes (or hopes) are "a little bit different" than the hope he gets from God. Different because "in every person there's a little bit of bad hope, but there's mostly good hope in people".

He explained his good hope with "well, my hope is that I can get through this big tough year and get back to in the swimming pool, diving in the pool...it's pretty hard". Swimming again for Tyler means that his cancer is gone. In one of his earlier counselling sessions Tyler told me that when his broviac was removed at the end of treatment, the first thing he would do would be to go swimming, because then he would know that his cancer year was over. The self portrait in Figure 6 shows Tyler without his broviac.



Figure 6. No more cancer!!

"I Just Double Hope"

What To Do When Hoping Is Hard

Together we talked of times when it is "pretty hard" to hope, or when we need more hope, with Tyler sighing, and saying "I've been needing, needing more hope for all this year that I have cancer". Tyler found that in the hospital "it's hard to hope that people will get better or not - that's really hard to hope about".

S- Yah, it is isn't it...so what do you do when it's really hard like that?

T- I just double hope.

S- You double hope...that's a good idea, how do you double hope, what do you do?

T- Try to find more hope...and use that hope.

S- So we try to find more hope, and use that hope, where would we go look?

T- Hope is all around us.

S- Ahh, so if I was fresh out of hope, where would, where should I go look...I come to you and I say, Tyler, I'm fresh out of hope, what should I do now...what would you tell me?

T- Um...close your eyes and relax and sorta ask for hope.

S- Ok, that's a good idea, now who would I ask?

T- Sorta, you sorta asking your body, you're, you're trying to think, but you don't say it, you're sorta telling your body to suck in some hope.

S- Kinda sit back and close my eyes and just tell my body to suck in some hope?

T- Yah, cuz hope is all around you.

S- Hope is all around me, and I just kinda get my body to suck it in.

T- Yah.

S- That's pretty neat...where does it go in my body?

T- It goes through your nose.

S- Mhmm.

T- Your mouth, your ears...

S- So that's how it comes in...where does it go to?

T- It goes all over the place.

S- Ahh, all over eh? What does it look like when it's inside there?

T- Looks like little white speckles, spots.

S- Ohh.

T- First it goes to your heart, and then the heart takes it with the blood.

S- Ok.

T- So it's dropped off.

S- It's dropped off everywhere eh?...does everybody have hope?

T- Everybody has it.

That hoping is sometimes hard is very real to Tyler, yet he seems to know what to do, how to go about getting hope, and has a clear idea of the process of his hoping. It is something he can do, whenever he needs to. He seems to find it easiest to talk about and picture his own hope.

Barley Greens and Essiac: Hope Helpers

When asked what had helped him through his big tough year so far, Tyler immediately said "barley greens and Essiac", which are herbal treatments Tyler's mother gave him throughout chemotherapy. Later, when asked what had helped his hope, he drew a picture of "barley greens in my mom's hand" (left) and a glass of water (right). (See Figure 7.)



Figure 7. Barley greens and water.

Tyler explained that the herbal remedies were helping by "keeping me out of the hospital", and then expressed concern that his Grandpa didn't want to take Essiac for the cancer in his leg. Tyler thought he should, "cuz then he'll get better faster".

Also helping Tyler get better were "alot of people hoping I get better". He specifically identified two really hopeful people - "my best friend's mother...whose house blew up, and another one of my friend's mother". According to Tyler, "they pray, they hope, that this, that I'll get better", which made him feel good, and brought a big smile to his face because he knew their hoping was helping him.

Tyler had a little trouble thinking of any other people in his life that helped his hope..."except spirits". Earlier in our conversation, Tyler had explained how he got his hope from God; "well, you know how God is a nice person, he just gives it to me, he gives it to people that loves him". According to Tyler, God also gave him three

special spirits that "help me feel better when I'm having a bad time, they look after me". Each person has their own spirits to help them. "God gave us these spirits and they just introduced themselves and I knew right away that they were mine".

Tyler's spirits provide him with hope, which they make "out of love". "They get the love from loving people like us" and turn it into hope with machines called "hope machines". Tyler wasn't quite sure what kind of machines they used - "to tell you the truth, I've never seen them do it", but he knew that the spirits were the ones that turn love into hope and "give the hope to everyone".

Sharing Hope

S- Once you've got your hope that God gives you, can you share it with anybody?

T- (nods)

S- Who do you share your hope with?

T- My friend whose house blew up...well, I just hope that his house gets built, and that he's happy again.

Tyler's best friend Jimmy lived down the block, and had had to move away temporarily as his house was being rebuilt after an accidental explosion. Together Tyler and I explored what we could put into a hope kit to help Jimmy hope. (See Figure 8.) Tyler knew just the thing - "a picture of what his house would look like", complete with a carpenter, plumber, "electric guy" and "the guy who puts the cement around the fireplace" to get the job done.



Figure 8. A hope kit for Jimmy.

Sharing hope and hoping for other people is important to Tyler, "cuz people that were really sick wouldn't get better if we didn't hope that they did...I'm hoping that my Grandpa gets better".

As we finished our exploration, I asked Tyler what else people needed to know about what hope, and suggested he make an ending for "hope is..." as a final message. Tyler feels that people should know that "hope is sorta love".

Reflections on Tyler's Hope

Of the four children in this study, Tyler appears to be the most independent about his hope. He does not link it directly to his mother, family, friends, or doctors and nurses. Tyler's hope belongs to him and is something that he can actively do. Tyler's hope has a spiritual base, and is provided to him by God and spirits. While

hope is inside Tyler, it is also all around him in nature and is something to which he makes himself open.

Tyler sees hope in things beyond. Beyond his family and friends, who are of course helpful, Tyler relies on God. Beyond conventional treatment methods, Tyler looks to barley greens and Essiac to help his cancer. Tyler is only six years old, yet much of his hope reflects his experiences to date, and likely the values he has learned from his family. It is, for instance, his mom's hand that he draws giving him the barley greens and water to take which help his hope. Tyler is not, however, simply repeating things he has learned or heard about hope. He clearly has his own hope words and experiences and has incorporated hoping into who he is.

There is something about Tyler that is different. It is difficult to explain, but parents, doctors, nurses and even other children remark at how he is in the world, how he approaches and looks at life. Perhaps his hope is part of this something different.

Shortly after our second interview I began to discuss the possibility that because Tyler was off treatment and doing so well, he would no longer need to come and talk with me on a regular basis. I encouraged the progress that Tyler had made in controlling his mad attacks, and we talked of his strength in relation to dealing with his cancer. Tyler readily accepted my encouragement, and agreed that he was doing very well, but would not entertain the idea of stopping our sessions. Over the next three months I increased the times between Tyler's sessions and we finally agreed that when he went back to school in September he would not need to keep coming to see me. As it turned out, Tyler's grade one teacher is a friend of mine, and Tyler and I agreed to pass messages and "hellos" through her to keep in touch. I wonder if his meetings with me were part of Tyler's hope.

JESSIE

Meeting Jessica

The inpatient unit felt warm to me that winter morning in January 1994. I remember having to don a yellow hospital gown, the kind that never ties quite right, before entering Jessica's hospital room to meet her and her parents for the first time. Seven year old Jessica had recently been diagnosed with high risk acute lymphoblastic leukemia, and was susceptible to infection. Jessie was sitting in bed when I entered, surrounded by a colorful Barbie comforter. She had shoulder length blond hair and a shy, pretty smile. During that initial visit Jessie told me about her family (mom, dad and two older brothers) and what it was like to live on a golf course. She especially wanted to tell me about her dogs, two chow chows and a smaller furry dog, that she couldn't wait to get home to see.

"I Don't Like um Having Cancer"

Jessie Living With Cancer

Jessie underwent chemotherapy treatment for her leukemia both in and out of hospital from January to July, when she received her last inpatient treatment. Treatment for Jessie involved having a broviac tube inserted, losing her hair, and having to spend considerable amounts of time in hospital. Together with her mom, Jessie found innovative ways to create the illusion of real hair with hats and clever use of hair pieces. Her pictures are still shown to little girls facing the shock of losing their hair. Jessie is currently in remission, requiring only regular maintenance outpatient visits.

After our initial session, I only saw Jessie to wave and say hello as she passed my office on her way to clinic appointments. She had excellent family support, adapted very well to living with cancer and didn't feel she needed anyone extra to talk to. When approached by a clinic nurse in June about exploring hope with me, both Jessie and her mother readily agreed. Jessie thought it might be fun.

Exploring Hope With Jessie

Our first interview was held in my office at the hospital, but when we planned our second meeting, Jessie asked me to come out to her parents' golf course so I could see where she lived and get to meet her dogs. Jessie and I met at the pro shop and she began a tour of the buildings on the property. We stopped at the restaurant to get Snapple drinks, and then went back to the house where Jessie introduced me to her three dogs, who appeared to be good friends of hers. Jessie's mom suggested we talk in their school room, but after going inside Jessie said it would be better to do it right in her bedroom so she could show me her "stuff".

When Jessie arrived for our first session, she was talking about hope before she even got into my office.

I think hope is like, it's like you had cancer and you say I hope you get better soon...or I hope that you get well, mmm or I hope that you get me a present or something...or I hope you come back from the army or from your birthday party or something and...or I hope I get a cat...

When asked initially, Jessie indicated that all of these hopes were the same kind; hoping to get a cat, was the same kind of hope as hoping to get better from cancer. She later changed her mind.

Jessie's Hope Picture

Jessie titled her hope picture Get Well Soon!! (see Figure 9), saying that "it's a little girl laying in the bed, and the girl that's standing up is her sister, and her sister's saying I hope you get well soon, and the little girl says thanks". Jessie explained that the girl was a patient at the hospital "because she gots cancer".

get Well
Soon !!
↓



Figure 9. Get well soon!!

I explored with Jessie who the girl was, and although she said she didn't know the girl, she had often felt like she was the one in the painting, only then it would have to be a cousin or her mom who was talking to her, because she doesn't have a sister.

"I Always Say Hope Alot"

Jessie's Hope

Jessie talked easily and openly about her own hope, saying that "I hope that I get well soon, cuz I don't like um having cancer". She explained that hoping was hard for her sometimes; "when I first got cancer, I thought it wasn't going to go away, and

it scared me alot and my mommy told me it was alright, but I still thought it wasn't going to go away, and it really scared me". It was also harder for her to hope when she was worried about something like the surgery to get her broviac; "I was really scared like I hope it doesn't hurt, I hope I don't wake up in the middle of the um surgery and like it really scared me". During our second interview when Jessie was finished chemotherapy, she talked of "hoping that I don't get sick again, that's sorta scary hoping, cuz you don't know if you're going to get sick again".

Times of uncertainty and fear made hoping harder, but they were also the times that Jessie needed hope the most. "I did, well, I sorta did alot of hoping that I wouldn't like I always worried that I would, like die or something, but I haven't died (sigh)". When she needed to hope, Jessie would "just think about hope lots". "I just like thinked in my mind I hope that I like I hope...that I get better and it happened!"

Jessie believed in her hoping ability, and I asked her to help explain it to me in more detail. "It's inside me, in my heart. Hope comes from your heart and your brain. When I talk about it um it comes out of my mouth...it comes out and it says I hope you get better, I always say hope alot." When I asked Jessie what she would tell me to think about if I needed more hope, she instructed me to think "happy thoughts, like a sunny day, going to the beach, going to school, um loving a person".

Dogs and Gummy Bears: Hope Helpers

Although hoping is something that Jessie can do for herself, she also relies on others to assist her. When it was really hard to hope, Jessie would "usually cuddle with my mom, and she usually tells me it's alright and try to calm me down...it's hard". Jessie said her mom could give her medicine at home, look after her and give her the right foods to eat, but she picked her mom as her biggest hope helper mostly "because I love her (and I also love my dad)" and "she um doesn't make me worry".

Other people helped Jessie's hope by making her feel better, both physically and emotionally. Her family played a large part in the latter. She spoke specifically about her brothers, saying

well, when I first got leukemia, um they brung me lots of presents, and um they say I hope you (like I was playing cards with them) and they said like I hope you get well. Or sometimes they say to me Jessie, I know you're going to get

better and that makes me feel happy. They gave me gummy bears (she smiles) and they came and visited me everyday in the hospital.

Jessie also felt that her doctors and nurses at the hospital contributed to her hope of getting well. To explain hope to the child from another planet, Jessie decided that acting hope out would be the best way to show it.

You could um get some people in your class and like the person from the other planet could be um in another chair watching us act it out...um, someone would be laying on the bed, and and I, someone could be the doctor, and someone could be the nurse, and um they are helping that patient get, to get better, and they're giving medicine to the person and um they're laying down on the bed and got pills, and IV pole and like a broviac and arm pokes and stuff.

For Jessie, the doctors and nurses are the ones that can "get rid of your cancer". Her favorite doctor also helped her hope by being "very funny, and very nice" and trying "to make you sorta don't worry." Jessie placed a certain trust in the medical staff.

Well, they said Jessie don't worry, it's not really scary and we'll try and make you better and stuff, and that made me feel much better when they say that stuff because I know that I'll get better if they say that.

Jessie also thought people should know that besides coming from doctors, hope "comes from like your heart...or it can come from your dog or your cat or something. I just love dogs so much, they give me lots of hope." Jessie likes holding her dogs, looking after them and especially sleeping with them. She wasn't sure exactly how they help, but her dogs make her feel better.

Jessie's Hope Angel

During our second interview, as we began to talk about how hope is shared, Jessie jumped up saying "oh, can I show you something?" She left her bedroom briefly, returned with something in her hand and said "here's hope". No explanation, just "here's hope". When Jessie opened her hand she revealed a small white ceramic angel. The angel is kneeling and has a little butterfly on her wings. She is gently used, having a tiny chip out of one wing, but this only makes her more precious. I asked Jessie to tell me the story of her angel.

Well, when I was sick um this man he um gave me my, gave this to my mom and it was sort of for me...he didn't know my name and um, well, he said "Here's a present for you Jessie" because my dad told him and then um I opened it up and it was a little angel. And I said "what is it for?" and he said "well you're sick and when you get better and someone else that you know gets sick you pass it on to the other person and then the other person would get better and the other person will pass it on to another person that's sick."

No one told Jessie that what the man had given her was hope; she said she "sorta decided it" on her own. Jessie is not sure if she will pass the angel on to anyone, at least not yet. She still needs to hang onto it "because like I'm not done yet". Her little angel makes Jessie feel "really happy" because angels are "so pretty and they can sorta help you think about the nice hope". We talked about where her angel might have gotten the hope she gave to Jessie, and Jessie thought it might either be from the way the angel looked, or from God. "Well everybody knows that God's really nice", and that "God gives everybody hope".

"It's O.K. To Have Cancer": Sharing Hope

Just as others helped Jessie with her hope, she thought that she too could "sorta share with it". She had some good advice to offer other children who might be told they have cancer.

I would like tell them that it's ok to have cancer, you just don't have to think about it, but it's hard to think about it, hard not to think about it, um, there are lots of things, don't worry because um you won't have cancer forever and your whole entire life.

If Jessie could pack a hope kit for such a child to take to the hospital she would fill it with

a little card that says I hope that you're not scared and that you get better. You could put a teddy in it, and some little candies, and um a little toy, or a little like like um what is it called, a little rubber spider to play with or something, or like it could be a little teddy, and then there could be a big teddy, with a note in it and the little candy.

In her own hope kit, Jessie said she would also add "a picture of my family".

As we decided to end our exploration, at least for now, I asked Jessie if there was anything else that she would like parents or children to know about hope. Her answer was simple... "hope is love".

Reflections On Jessie's Hope

Jessie's hope is strongly connected to love. She finds hope in the love and comfort of her immediate and extended family. Smiles and presents from her brothers and cuddles with her mom help Jessie's hope. Of the four children, Jessie expresses the most trust in the medical treatment she received. While the other children look beyond treatment for hope, Jessie is able to see hope in the medicine and especially in the words and actions of her doctors and nurses. This too may be a reflection of the attitudes of her family, and where they place their hope.

For Jessie, hope is protective, and can stand between her and difficult things such as hurt, fear and worry. She appears to draw hope from the verbal messages expressed to her by family, friends and medical staff. Hearing others say they are hoping for her, or that they know she will get better is important to Jessie's hope. While her hope is largely in the care of others, Jessie also has her own hope sources such as her dogs, and her hope angel. Again, hope is something Jessie can do, but is also something with which she sometimes needs help.

CURTIS

Meeting Curtis

Curtis was referred to me for some help in dealing with living with cancer. His treatments were nearly complete, and he was returning to school. During our initial session in March 1994, Curtis spoke openly and knowledgeably about his cancer experience, in a serious, almost adult manner. He explained that he was coming to the hospital for radiation "to get rid of the rest of the disease". He also thought he could use some help in making some more friends at school, because he had missed the beginning of the year when everyone got to know each other.

"I Feel Like The Victim Of A Crime"

Curtis Living With Cancer

Just as he was beginning his grade two year, Curtis was diagnosed with a brain tumor, called an astrocytoma. He immediately underwent two surgeries to have the tumor removed, and then began radiation treatment which lasted from October to March. Some of his hair was shaved for the operations, but it grew back quickly, and he did not lose his hair during radiation. Curtis had persistent difficulty with double vision, which was especially frustrating for him because he loves to play baseball. Although batting and catching were made more difficult, Curtis persisted, practising extra hard at home with his dad.

Throughout his treatment, Curtis was determined to put his tumor behind him. "I think my cancer has been growing for over a year, and I still haven't felt anything". Curtis sometimes expressed concern and anger that people were so worried about him. As far as Curtis was concerned, his tumor had been found, and then removed by surgery. He was certain it was gone, and he wanted to get on with his life. In contrast to the other three children, Curtis did not endure lengthy hospital stays, broviac insertion, infections, and repeated pokes for blood work. In fact, he considered himself lucky not to have had chemotherapy to "poison the cancer". Despite trying to put the tumor behind him, Curtis expressed feeling like the victim of a crime. He said he knew he hadn't done anything to be punished for, but that having cancer sure felt like punishment.

Exploring Hope With Curtis

Curtis and his mother both agreed quite readily that he could be a hope explorer. Curtis approached our initial interview with interest, easily becoming absorbed in his hope painting. He thought carefully about his answers to questions, and seemed genuinely interested in the topic. On his next visit, however, Curtis was less willing to participate. He did agree to talk a little bit more about hope when I explained I had also talked to other children, but after about half an hour his interest waned and he felt he had said enough.

Curtis' Hope Picture

Curtis painted a person lying on an operating table, saying "ouch!" (see Figure 10). The person wasn't anyone particular, but according to Curtis, "let's just say they got their tonsils out and it hurts like wild". When I enquired what about the picture said something about hope, Curtis seemed upset that I couldn't just see it without him explaining it to me.

C- It's look at the picture...how do you think that person feels?

S- My guess would be that that person is in pain, and that person is probably scared...

C- Exactly!

S- Mhmm...so, what do you think this person is thinking? If he could say something to us, what would he say?

C- It hurts.

S- Mhm.

C- My reason of hope, is that nobody else...gets any cancer or ...anything. For Curtis, his painting depicted "a time when you really have to hope - when you're sick and it hurts".



Figure 10. When you're sick and it hurts.

Hope Is Just a Word

We went on to explore other ways to image hope, talking about a possible size, shape, or color that hope might have. Curtis did not "see" hope this way. He had "no idea" what hope might look like, saying repeatedly that "hope is just a word...a plain word". Curtis knew what hope was, but it couldn't be described within the framework

I was suggesting. When asked how he would explain hope, Curtis replied "I'd say, if somebody is sick, and they want to be better, that's hope, that's it".

"I Know My Cancer Is Going To Go Away"

Curtis' Hope

When first asked about his own hope, Curtis denied hoping. "I don't hope about anything, I know my cancer is going to go away". Interpreting that as a hope-filled statement, I encouraged Curtis to tell me what helped him get through the time of his cancer. Just "being alive" through everything was important to Curtis, and made him feel good. He also mentioned his mom as the person who helped him with his hope. (It seemed that once Curtis had let me know that he didn't need to hope, he was quite comfortable continuing to talking about it.)

He identified his mom as a hopeful person, saying that she helped his hope by making him take vitamins and garlic pills. When his mom would say "take this, take that, take this, take that", Curtis said he knew that she wanted him to be better and that she was hoping "to get rid of my cancer". Curtis also thought that his mom prayed about him. He knew for sure that his grandma prayed for him, "but I don't know exactly about my mom". Curtis thought praying was "a good thing to do, that might help, that's like hope". He even does it himself sometimes.

Hoping

Although Curtis knows that his mom helped his hope, hoping is also something he can do on his own. His hope is "just in me", and is something Curtis was born with. "Let's just say, it starts out low and the bigger I get, the higher it goes". I asked Curtis to help me understand how I could go about hoping. He instructed me to "think of life", and if I wanted a good life, to just "hope for it". Curtis didn't elaborate on how to "do that", but suggested that I "just don't get sick, for one thing". He also offered that "planning something I really want to happen - that's hope, at exciting times". At other times, Curtis acknowledged that "it's really tough to hope, sometimes you have to do stuff", but didn't have much advice on what that stuff might be.

Hoping for others is also important according to Curtis. If "say you get sick, that's how you hope. If somebody else gets sick then you can hope about them". To share some hope, Curtis agreed to put together a hope kit for someone else who was sick. "Well, let's just say, he's sick, and we would put a message: If you're sick, do you want to be better?...and then, if he said yes, he's hopin'". I asked Curtis what we would do if the person said no, and he replied, "I don't think he would say no". Not hoping just wasn't an option.

After all, "you need hope because there's a bigger chance that, probably a bigger chance um that the other person might get um well, might get better". We began to talk about times when we really need hope, and Curtis said that he had had a time like that, but didn't want to share it; "it was just a bad time, that's all, just a bad time".

At this point, Curtis stopped the tape recorder, saying he had some private things to say. I received his permission to write what he said down on paper if he didn't want to say it onto the tape.

C- The one thing I want to say is, hoping for people is good. If someone is sick, you ask them "do you hope you're better?" Cuz if you don't hope, you haven't got a chance. I really do hope I get better, even though I know I will.

S- What else?

C- If you are part of the family you can hope too. But really, the only thing that helps people hope in the hospital is themselves. The doctors said I was brave.

S- What can you tell me about being brave?

C- Well, it's just like I believe I can do it - it's like hoping. You know you can get through the needle, so you just hope it won't hurt. I know it won't hurt, but I still hope.

Even after talking about his own hope so openly, Curtis later reemphasized that hoping was something he didn't really do "so much because I don't really have to hope cuz everything good really happens".

Reflections on Curtis' Hope

For Curtis hope is very personal and private. It is not something he readily admits doing, but he has quite a bit to say about it in private. He realizes it is essential to getting better, but seems hesitant to rely on it. Although he hopes, perhaps admitting to hoping makes Curtis feel that he is not being true to his "knowledge" that he's going to get better. I wonder if Curtis' hope lies in his certainty that his cancer is gone, and in the comfort that he doesn't have to hope. He knows he will get better.

MICHAEL

Meeting Michael

It seems now that Michael and I never really met. We first saw each other when he came to my office to participate in the hope exploration. He was waiting with his mom in the hall when I approached, and from the moment we said hello, he treated me as if we had always known each other. Michael has an easy, friendly manner, and seems older than his nine and a half years.

"I Didn't Want To Have Cancer In The First Place"

Michael Living With Cancer

The month before his seventh birthday, Michael was diagnosed with T-cell acute lymphoblastic leukemia. For all of the time he was seven, and all of the time he was eight, Michael was on treatment for his cancer. Like all children with leukemia, Michael received intensive chemotherapy. "I had chemo yah, well that helped, but like I didn't want to have that stuff, I mean I didn't want to have cancer in the first place". Also like other children, Michael lost his hair.

I was completely bald, I hated it, and now I got my hair back, and it will stay hopefully - until I get old, really old, but I'm, I'm only nine years old, so I'm not talking about that now (laughs), cuz I'm not looking forward to losing my hair again.

For children with leukemia, having chemo and being bald become pretty routine, but Michael suffered more from other complications related to his treatment. He endured recurrent infections, and also had great difficulty with his esophagus. His esophagus kept constricting, which required regular procedures to dilate it again. According to Michael,

well it was, I had a stretcher, they had, they had to um stretch my throat every uh few weeks cuz it got smaller, my esophagus did, cuz it, I had fungal a fungal infection and um they put this stuff on me and well I kept uh I kept being nauseated and kept vomiting lots, so what happened was...that harmed the scar tissue as well.

Michael's cancer is currently in remission, and he is off treatment, but only days before our first interview, he had had stomach surgery to help correct some of the complications. The effects of having had cancer still linger. Michael said he'd "give up all my time, all my free time just to just to not have cancer".

Exploring Hope With Michael

Michael and his mother were first told about this hope study by a nurse at the clinic during one of Michael's check up visits. Before I had a chance to follow up the letter of introduction with a telephone call, Michael's mom had phoned me to say that Michael was interested. He was off school recovering from his surgery, but said he felt well enough to come and see me just to talk. He thought it would be fun and interesting to talk about hope.

During our second interview, Michael elaborated on what he had said the first time we talked, and also told me his intricate plans to one day build a gigantic seaworld. Because Michael refers to his seaworld when talking about hope, a few details are included here. Michael explained that he had "already planned my whole life out, basically", and was going to create "Awesome Waters". According to Michael, Awesome Waters will have seals, dolphins and sharks just to name a few, and will also include a waterslide, snorkel place, "Octo's arcade", and a restaurant. Michael's goal is to help the sea creatures "because, well, I don't want them to die".

Michael's Hope Picture



Figure 11. Mom the hopemaker.

For his picture, Michael was "going to pretend I'm in an operation, my hair's straight up". The operation was a lumbar puncture, where the doctor used a "big needle" to extract some fluid and "inject something". Michael drew "a cover on the bed, one of the sick beds" because "I usually hold my hands on top of the covers - oh yah, I'm using the other hand to hold my mom's, she usually holds my hand". Michael said he "was kinda freaked out at that LP stuff" and would have been thinking "don't do this to me, I'm in really lots of pain...I also thought that if I got it over and done with, maybe it would go faster, but my mom was there...and that was hope".

Mom the Hopemaker

Michael's picture depicts a time when it was hard for him to hope. It was

just about two and a half years ago, um, I was just diagnosed, and that was probably the hardest part. I didn't have much hope that I think, that I was actually going to survive this much, but now, I look back on it and just think that my mom gave me hope and stuff and that was, that helped alot, that she was there.

Michael also talked of his mom playing with him, making him "laugh when no one else could", helping him to be happy, and just talking with him to take away some of his worry. "She usually helped me deal with the things, cuz uh, cuz she was there it made me feel alot better, so that was one medicine the doctors couldn't give me, it was good to have my mom there".

When asked to choose a title for his picture, Michael quickly replied "Mom, the hopemaker, probably - yah my mom was the one that brang me most, all of my, almost all of my hope, about 90% of my hope". He wasn't sure how he got it from her, but maybe "because of her being there and holding my hand and stuff, that deals with some of the pain and that was hopeful". He said his mom "usually got my eye off the needle and that's half the pain". Michael's mom provided distraction and reassurance. "Well, when my mom told me something and then my mom said agh, this'll be a piece of cake or something, I had hope, and it felt good that I could that I could have hope".

A Refreshing Feeling

Michael had difficulty elaborating on what it felt like to have hope. "It's just a refreshing feeling...like uh, I wouldn't have to worry about this one thing and that would be good". He has hope "in my brain usually, um cuz it, whenever my mom talks about it, there it is". When Michael tried to think of a way to explain hope to others, it was again "a refreshing feeling" that if something is going to happen to you "it will be really good, instead of really bad...and you hope that it actually will be that and it usually is". Hope usually works. If he could, Michael would show people a tape of his mom to explain hope; "they'd probably understand that, like my mom holding my hand, that was hope for me".

Imagining what hope looked like was not much easier for Michael. He "didn't really have a hunch", but thought it was probably "a good thing that comes in your body, usually when you think of it". Asked about a color for hope, Michael thought

maybe "red or pink, cuz that's usually a sign of love or something". He again talked of how good he felt when his mom was around; "that made me really happy...I loved her alot". He also "trusted her alot, so that always helped". According to Michael, "if you really love someone, you really trust them too, so it also means that like, that when you trust someone, you know that that they're that they're telling you the truth, and telling you it won't be bad, and well, that's hope". He also "believed her, and that's hope".

We went on to talk about the size of hope, which Michael said depends on "how much hope you feel in your body, um, if you feel alot of hope, it will probably be, probably about this big (the size of a softball), but if you have really teeny hope, it might look like the size of an ant. Ant size wouldn't be enough, that would mean barely believing, but big hope means you really believe it, and I really believed it". Belief, love and trust are important aspects of Michael's hope.

One Hundred Percent Hope: Who Else Helped?

While Michael's mom was "basically the thing that got me through" the cancer experience, he knew she was not the only one. When he was asked about the other 10% of his hope that didn't come from his mom, Michael talked about his dad and his eleven year old brother who visited him in the hospital, and generally made him feel better. Michael rated his hope "on a scale of one to ten, probably a nine when my mom is just there, and a ten when my whole family's there".

Michael explained that ten percent of his hope came from himself, and the rest he got from other people, "and if there's ten people combined, you have a hundred percent yourself". Michael

never had one hundred percent hope all the time, I mean sometimes I had fifty, sometimes I had thirty, sometimes I had twenty... cuz people say this is going to hurt, I mean you're likely to believe them, so back to like five percent hope....When people say this'll be great and it'll be fun or this'll be okay or it won't hurt at all,

his hope would go back to ninety-five percent. One hundred percent hope only happened "a few times, um sometimes when my whole family was there".

We also talked about people in the hospital, and what role they played in helping Michael's hope. The hospital is not a hopeful place to Michael. "All there is is needles, and those sure don't bring you hope". Michael perceived that doctors and nurses "didn't do much, I mean they helped a little bit, but they didn't really deal with any of my pain...they'd just get frustrated and leave". Michael identified one doctor in particular who was nice and cheerful and "he was really the only doctor who would stop by not to do something, just to talk". Medication didn't do much for Michael either. "Medication didn't do much at all actually, medication helped a little bit, very little, it didn't calm me down or anything, it just put me to sleep or something". What really helped in the hospital was the comfort of his mom, "she was like a million nurses, she'd never leave me".

In addition to the people in his life, Michael mentioned God as being important to his hope. While we were discussing the difference between wishing and hoping (see details in Chapter 5), Michael remarked that "God responds to hope, but he really doesn't respond to wishes, I mean he's not a genie". I asked Michael what he thought God had to do with hoping.

Well, sometimes, he'll help you get through it, I mean, I don't know...who gave this to me...but he helps you get through it by uh basically letting you live, because God takes you away when he wants you, not when he doesn't want you, I mean, not that he doesn't like you or anything, but when he feels that you have had your life and it was a good one, but so far, I mean, cancer, I mean so far I had an okay life, but having a great life would probably be like living to ninety-seven.

A Hopeful Friend

For Michael, hope clearly "isn't something you just can do by yourself, I mean you need other people to be there, that's what helped me alot". Ricky was one of those people for Michael. Ricky, who also had cancer, and Michael were close in age, and became friends during their hospital admissions. When asked about hopeful people, Michael responded "mmm, probably me and my friend, well, probably my used to be friend um Ricky, he died of cancer, he was very hopeful and he was always smiling". Michael and Ricky spent time together in the teen room, playing, making crafts and

using the computer. According to Michael, Ricky "was a really constructive person" who always "did all he could do". Ricky "was hopeful, he was, I betcha he had lots of plans as well to get through this, but he wanted to get through and he was hopeful about that, (sighs) he didn't make it, and I still have a picture of him...".

It was hard for Michael to lose friends to cancer. "Well, it gave me some doubts, doubts that I will get through this, I mean, they died, I don't know if I'm going to make it either, and I was, I was scared sometimes, I was just scared, I mean I didn't want to die, I had so much planned, and if I die, I mean...". Members of Michael's family also passed away during the time he was being treated for cancer. His grandpa and his uncle both died, "and that didn't help at all because when I had cancer then too and like that did not help (sighs) yah that did not help, that did not help calm me down". Michael saw these difficult times as assaults on his hope. He told me a story about a dog he once had which illustrated this well.

I should bring my picture book, my dog was in there, that I used to have, I miss him alot, but that was a sad thing in my life, I had hope when he was there because, well, I hoped that he'd be there the next day, but then we had to give him away...I was very, very...well I didn't have much hope then, but then after awhile I got used to having hope again...when bad things happen it usually, it's like a war and it wounds your your hope or something when something sad happens, but then, but then it's like your hope um heals and it's coming back. Asked how hope heals, Michael said "it does it on its own basically, but you have, well no, actually it doesn't - you have to feel happy again, and you can't just feel grumpy anymore...yah, feel happy and you'll feel hope".

Signs of Hope

Things that made Michael feel happy and hopeful, he named his "signs of hope". Webber the Platypus, a stuffed animal that accompanied Michael through his ordeal with cancer, was his "first sign of hope, because I won, I won him in a draw, so I knew that I could actually get something". Webber just being with him was another way that "he helped with hope as well". Crafts also made Michael feel good; "I love making crafts, and those are usually a sign of hope for me, because I love my work".

Having stuffed animals around, and doing crafts really helped Michael's hope in the hospital, as did the visits of a real dog named Tippy.

According to Michael, Tippy is an essential part of treatment for kids in the hospital. Tippy

makes them get more hope because he's a dog and that usually, that usually makes people have hope, because, because of him being there...he's a friend of the hospital, so that animal's allowed to come in. They also have this big dog in, that's a real big one, and he has these little wire, this little dog that has those big circles of hair coming down...I thought, I thought he looked funny...he was my favorite all the time.

These dogs help the kids hope "because they are there, and they uh they're fun, they make people smile, and that's also a sign of hope, because um them thinking that that's good and looking forward to, and they hope that they'll be there next week".

Sharing Hope

Michael and I also explored what other kinds of things might help children with their hope. He had some good advice to offer.

Well, you could tell them that you've been through this, if you really have and tell them that it'll be alright, and they'll probably have alot of hope if they trust you...probably that it'll be ok, and mmm, that's what hope is...if if you really think it's that bad ask someone who has had it, and ask, and they'll probably say that it doesn't, it isn't.

Thinking about other kids who had cancer reminded Michael of a little boy who was in hospital once at the same time as Michael. "I remember that there was this little kid in the hospital, he just had surgery, and his mother wasn't there...for about, about two weeks, he was alone, he probably didn't have any hope...I felt sorry for the guy...it was crazy too that his mom wasn't there". We decided that it might have been a good idea for this little boy to have a hope kit, and explored what could be in it.

Michael thought that "probably a mom...and your brother and dad" would be helpful to hope, and "well, maybe a stuffed animal or two, if you're really young, you believe that they're alive or something and that's always good". Michael thought that when a kid is sick, especially in the hospital,

parents should know that they that they should be there, because well the kids need them there...for hope..and doctors should know that and, like they should have, like in that hospital, one parent can stay so they have this little chair that folds out into a bed, well I think...every hospital should have one of those, if any kid's staying there...it's a world better if your mom or dad's there. It would even be better if there could be more beds so that "your dad and and brother could sleep there too, that would make it alot more hopeful".

Disease-hope or Fate-hope

As Michael and I were finishing our second interview, I asked him if there was anything else he wanted to let people know about hope. Interestingly, after all we had talked about, Michael said "well, I don't think many people are hopeful about many things". I encouraged him to explain what he meant.

M- Well, if you don't really have, if you don't have some kind of disease, maybe my friend Jason, he has asthma, he's hoping that someone could get a cure for asthma, I mean he's born with it, it's something you're born with, not cancer though.

S- So would you say that the kids in the hospital that you got to know would they be on average more hopeful or talk about hope more than the kids in your class at school?

M- Mmm, yah, cuz when you don't have a disease, sure you hope you have good luck the next day and you hope that your friends are home, but like you might hope that your mom is nice, but like,

S- It sounds like that is a different kind of hope

M- Way different kind of hope, I mean there's hope-hope and then there's fate-hope, I mean,

S- And which is which?

M- Well hope-hope would probably be like "I hope that I get good luck", fate-hope would probably be like "I hope I get through this, but if I don't I mean..."

S- Do you have them both?

M- Well, sometimes, I mean I hope I have good luck every day, and that I'll get through this some days and so on.

S- I think that's an important thing that you said you know, the hope you have with a disease is a little bit different.

M- I mean like I was talking about earlier about that awesome waters, that's hope-hope, that's not disease-hope, I mean awesome waters isn't a disease, it's a place...it will, hopefully it will be place.

S- Do those two kinds of hope, you called one hope-hope, what's the other one?

M- Fate-hope.

S- Fate-hope, are they in a different place inside you, or do you get them different ways?

M- Not really, they'd probably be in the same thing, but like if you're not in the hospital, your body will see that and you'll just have hope-hope, it's different that way.

S- Do you think you have to have something like a disease before you can get fate-hope?

M- Not usu..., not all the time, I mean, if someone tells you that your heart is on their las, your last beat, I mean, or you're only going to live for another day, that's fate-hope as well, you don't always have to have a disease, sometimes it's just...

S- You sound like you know alot about this.

M- Well, (chuckles), I've had hope for a long time - two and a half years is a long time.

S- Did you have hope before you got cancer?

M- Yah, I had hope then, that I'd have good luck the next day, just hope-hope, but I never had fate-hope before, until then, but...first of all I didn't even have fate-hope, I never had any hope.

S- At the very beginning.

M- Right, at the beginning, now I'm fine, and healthy, wealthy and wise...well, not the wealthy part,

S- But healthy and wise...and with the healthy and wise you can get the wealthy right?

M- Hopefully...anyway.

Michael distinguishes fate-hope from the everyday hopes we speak of so frequently. And he knows the importance of fate-hope. "The more hope you have the more you feel better that you'll get through this (cancer)...You actually need hope, if you're actually going to get through something without, well, without being really unhappy and grumpy at the end".

Reflections on Michael's Hope

Michael talked easily about hope. For him hope is not an abstract concept, but rather a part of who he is and what his experience of cancer has been like. Hope for Michael is his mother. His hope is linked directly to his mom, and is dependent on her presence. Because Michael's hope is largely external, it is quite fragile and fluctuates with the coming and goings of his mother. "When my mom walks out the door it doesn't shatter hope, it just...she walks out the door and when she comes back...it (hope) comes right back".

Although Michael depends heavily on his mom for his hope, he is able to see hope in other things, and has many interesting thoughts and ideas on helping other kids with their hope. Michael emphasizes the importance of hope and captures the difference between everyday hoping and the kind that is necessary to children who are really sick.

V. CHILDREN'S HOPE: A DISCUSSION

Hope frees our hearts to live and love. It fills the soul with new visions of what we are and who we can become.

(Author unknown)

Before beginning this chapter, I encourage the reader to return to the words of the children in chapter four, and to reread the children's ideas on hope. Perhaps read them slowly, letting the words and the children become real to you. For it has been by immersing myself in their language, pictures, phrases and examples that I have learned from their wisdom and honesty.

In presenting what I have learned and come to understand about these four children's hope, I combine the children's words, my interpretations, and interplay with existing literature, in sections entitled Approaching Hope, Hints To Hope, The Importance of Hope, Helping Children Hope, and Pieces of Hope. These sections are not presented in order of importance or value, but instead follow the general order by which my explorations with the children seemed to naturally unfold.

Approaching Hope

Hope Pictures

At my request, a hope painting or drawing was each child's initial expression of hope as we embarked on our hope exploration. As soon as the paper and paint or markers were within reach, Tyler, Michael, Jessie and Curtis were creating. There was no hesitation, no questions, no "I'm not sure what to make", or "I can't paint hope", or "I don't know what you mean, a hope picture." Each child knew what I was referring to when I asked for a hope picture, and eagerly gave shape, color and meaning to hope. Such expressions of hope seemed natural and easy for them. Hope is clearly within what these children know and experience. They are close to hope. They didn't have to pause and think about what to paint or draw, or how to access hope. Hope was right there waiting to be painted.

The children painted and drew with assurance, knowing that what they were putting into picture was hope. With their first expression of hope, all four children created pictures which revealed the essential nature of their own hope. During the dialogue that followed the art work, hope was at some point connected to typical,

everyday hopes similar to wishes or wants, such as "I hope I get a cat" (Jessie) or "a hundred dollars" (Tyler), but that was not the hope expressed initially in picture. Through art, the children got beyond our limited language for hope, to really show what it is in their lives.

The hope pictures all depict difficult times or situations, where there is a need for hope. The children's pictures are of hoping, of hope happening, of hope in action. Although the pictures show times when it is hard to hope (having a lumbar puncture, or an operation), the pictures are not dark, dreary, or depressing. The pictures show a need for hope, but they are not hopeless. The need for hope is being met. Either a family member or friend is providing hope (Jessie and Michael), or the child is hoping for himself (Curtis) or for others in need of hope (Tyler and the forest animals).

While not hopeless or depressing, the pictures are not happy or hopeful either. They don't show pretty, sunny gardens of hope, or depict happier times ahead of the children at home playing with favorite toys or friends. The pictures reflect hoping, at times when it is needed the most. The pictures are hope-filled, because the situations require it. In creating hope pictures the children openly revealed when they needed hope, and how they went about hoping.

Each hope picture is unique and reflects hoping as experienced by its creator. Michael draws himself actually holding on to his mother, who is his hope. Jessie shows a girl in the hospital who has cancer, and who is hearing hopeful words from a family member. Curtis shows a scared little boy hoping alone. Tyler paints a forest that reminds him of his hope that animals won't die. As the children further explore and talk about hope, it becomes clear that their first expressions revealed much about their hope.

Michael feels that his hope is largely tied to his mother, and her touch, comfort and presence. Hope for Jessie is much more a verbal expression that she can take to heart. Hope is something Jessie does, but it is helped largely by family and friends. For Curtis hope is private and something that really only he can do for himself. Tyler says that hope is all around us, and draws much of his hope from spiritual sources. It is not surprising then that his painting is of nature and goes well beyond him and his family. The hope pictures reveal not only the children's unique experiences of hope,

but also the varying degrees to which they rely on outside assistance for their hope, and to whom they look for that assistance.

Hope Is Hard To Explain

While the children easily brought hope to life through art, talking about it was more difficult. Throughout our conversations, phrases such as the ones that follow, were offered by the children.

"Um, it's hard...it's sorta hard to think about hope" (Jessie).

"Well, I can't really explain it much" (Michael).

"It's really hard to explain, yah" (Michael).

"Hope is like, I can't really explain it" (Curtis).

"Probably something like that, I don't know" (Michael).

"Hope is sorta like..." (Tyler).

At times it seemed almost as if the children were at a loss for words to describe hope, or that the words they were using weren't really conveying what they wanted. It was much easier for them to show hope. Jessie brought me her little angel, saying "here's hope". Michael wanted to explain hope to others using a videotape of his mom being with him. Jessie would put on a play about being in the hospital to show hope to others.

Given our liberal and perhaps over use of the word hope in everyday language, I was impressed by the children's abilities to get past language limitations to explain hope. When plain words weren't enough, they used words to describe situations, "if somebody is sick" (Curtis), images, "hope machines" (Tyler), and signs or symbols such as Jessie's angel, or the dogs for Michael.

Trying To Describe Hope

After the children had painted or drawn hope, I encouraged them to describe hope to me by asking about its color, size and shape. Despite being able to picture it so clearly on paper, the children did not readily respond to my questions. They seemed to grasp for answers, such as offering their favorite color as a color for hope (Tyler and Jessie), or saying they just didn't know (Curtis). I had thought that children, with vivid imaginations, would have endless descriptions of hope, likening it

to happy, beautiful things that made them feel good. It soon became clear that I was actually discouraging the children from expressing hope. They did not want to talk about it in the abstract, they wanted to talk about their own hope, and how it is in their lives.

Once the children were allowed the freedom to express their own hope through stories about their experience with cancer, and examples of what they had been through and when they needed and used hope, their explanations were much freer, more colorful and alive. Perhaps in trying to protect the children by not initiating a discussion of hope in the context of their illness, I had risked leaving our hope exploration at only a surface level. The children's initial expressions, depicting what is really important about hoping, namely their own hope, should have been my clue.

With the children as guides, our explorations focused primarily on the children's own hope, specifically in relation to their illness. It was easier for the children to talk about their own hope, perhaps because it then had context and was part of them.

Hints To Hope

As in talking to children about most things, when I talked to children about hope, it was left to me to put the glimpses, the pieces, the snapshots of wisdom they offered together.

Hoping Is Like Wishing...Or Is It?

At some time during our conversations about hope, each child addressed hopes and wishes. It began with either "wish is like hope" (Curtis), or "it's just hope, like wishing" (Tyler). In some way, the two were connected and mentioned together. When the concept was first introduced by a child, wishes and hopes were very closely linked, if not the same thing. When questioned, or asked to explain further what they meant, the children began to talk about the differences between hoping and wishing too.

The following conversation between Michael and I represents the type of dialogue the children and I had when discussing hoping and wishing.

M- Well, wishes and hope are basically the same thing...uh wishes are wishing that you want to uh wishing that you'll get through this, hope is pretty well the same thing, that you'll get through this, so basically...

S- Would it be just as good to say "I wish I get better" and to say "I hope I get better"? or is there a difference?

M- Well, there's maybe a little slight difference, but I mean I wish, would be like if a genie came and and he granted you wishes, but hope is like...well you don't need a genie to grant your hope, I mean you hope, and you hope...

S- Who do you need to grant your hope, or do you just do it yourself?

M- No, you need people there, you need people to be nice to you.

S- But real people rather than a genie?

M- Yah, rather than things that are superstitious or something.

A few minutes later, Michael also said that,

I probably learned that uh hope is probably the best thing to have, instead of wishing, cuz wishing doesn't do much...God responds to hope, but he really doesn't respond to wishes, I mean, he's not a genie...a genie would respond to wishes, but there's no such thing as genies, so saying I wish, is just saying that I hope, but like genies would say "I wish I was, I wish I was getting better" it would be the same as saying ...no, I mean it won't work usually...sometimes it will, sometimes it won't...

Clearly, this is a difficult concept for Michael, and he is the oldest of the children I interviewed.

Although this concept is difficult, and at times confusing, the children demonstrated the ability to distinguish some difference between wish and hope, or between wish and the sort of hope we were discussing. According to Tyler, who said wishing was like hoping for "money", or "booting his sister out the door", wishing was "a little bit different" from the hope he gets from God. When asked how it was

different, Tyler replied that "in every person there's a little bit of bad hope, but there's mostly good hope in people".

Curtis also began by saying that "if we didn't have hope we couldn't wish that something would happen, wish is like hope." Asked if they were exactly the same, he replied, "well, yah, sometimes...when it isn't, it's like a wish, like, well this wouldn't really happen, but in a story, three wishes from a genie, that's not exactly hope." Curtis later agreed that he could wish and hope to God to get better, but he couldn't hope to a genie to get better, because "genies aren't real". For Curtis though it would be just as good for someone to say "I wish" or "I hope" you get better.

Although there remains some confusion about the relationship between hoping and wishing, Curtis and Michael are able to identify the fantasy aspect of wishing, and Tyler identifies the unrealistic kinds of hoping as separate from the hope of getting better. The children understand that the wishing to genies won't really happen, but they firmly believe that their hope to get better or make it through having cancer is real and possible. These children know that their hope to get better is not guaranteed. They know that some children with cancer die, and they have worried and been scared for their own lives, yet their hope remains.

The ideas about hoping and wishing provided by the children I interviewed contrast with those presented by Wright and Shontz (1968). Using examples such as "I would like to be a policeman", the authors suggest that children "can express hopes without needing to be concerned about outcome probabilities" (p. 324). The children I spoke with are very concerned about the outcome of their hope. They feel that their lives depend on it. "I sorta did alot of hoping...that I wouldn't die" (Jessie). "People that were really sick wouldn't get better if we didn't hope that they did" (Tyler). "If you don't hope you haven't got a chance" (Curtis).

Wright and Shontz (1968) maintain that reality issues do not enter into the hoping of children, saying that "children's hopes are equivalent to desires" (p. 331). If this were true, I would have expected children living with cancer to hope that their cancer magically disappeared, or to hope that they get lots of presents, or that they don't have to have any more needles, but they didn't. The children living with cancer hope for survival. This is not a fleeting desire that wouldn't matter if it didn't come true. It is hope they depend on, that they cling to and actively sustain. Perhaps it is

because of their reality surveillance, rather than a lack thereof, that these children hope as they do. They understand that their situation is very serious, and that it calls for hope of the most important kind.

Hinds (1988) in her study of hope with adolescents suggests that the "conceptual distinction is that wishing contains an element of denial of seriousness of a situation", while "hopefulness contains an acknowledgement of the difficulties present in a situation and a desire for those difficulties to subside" (p. 85). Michael, Jessie, Curtis and Tyler all realize the seriousness of having cancer, and live with the difficulties of their disease in hope of better times ahead.

What the children expressed in this study is also consistent with the writing of Korner (1970), who asserts that a wish is something "which might happen, but the person does not organize his behavior with the expectation that it must happen...In hope, however, it is exactly this quality of personal dependence on outcome which is its central characteristic" (p. 135). These children living with cancer are unquestionably hoping. They are "tied to their hopes; they need them; they resist losing them; they fight to maintain them" (Korner, p. 136).

Literature also suggests that hope is realistically possible, or in the realm of the possible, which distinguishes it from wish (Ellerhorst-Ryan, 1987; Dufault & Martocchio, 1985). Tyler, Jessie, Curtis and Michael may very well have wishes, in fact I would be surprised if they didn't. What we explored together, what they expressed to me through their painting, their words, and how they simply are in the world, however, hints only to hope.

Good Hope and Bad Hope

The hope we explored together was predominantly "good hope" (Jessie), the hope that sustains through illness, that provides comfort and helps against fear and pain. Yet the children also referred to bad hope. Not in the way we as adults might refer to false hope, or having too much hope, but as hope being used toward a bad outcome such as harm or death. As Tyler talked about God giving hope to people who loved Him, he added "but robbers don't get any".

S- Robbers don't get any hope?

T- Yah, just bad hope.

S- Bad hope, what's that kind of hope like?

T- The kind where people die, I don't like that kind of hope.

S- What kind of hope do you like?

T- I like good hope.

S- Like what, can you give me an example of good hope?

T- I hope that no one dies, but robbers hope that someone dies.

For Tyler, bad people hope bad things. Jessie and Michael had similar ideas that hope could be bad, but it wasn't necessarily tied to bad people like robbers. Jessie distinguished between good or "happy hope", and "not-very-good-hope".

Well, good hope is like really nice nice hope like it um I hope you get better and like really bad hope is like I hope you stay like this forever or I hope you get you never get well again. (Jessie)

According to Michael,

The only kind of bad hope is like hope someone will die, that's a bad kind of hope, or if you hope someone will get hurt, that's bad hope, there's good hope and bad hope...Good hope is probably that you'll get through this, that's good, but bad hope would be something like I'm gonna die, I'm gonna die, I'm gonna die, I mean that's not hopeful, that's bad hope.

It appears that the children are aware of what the opposite of hoping, or of good hope is, yet the only term any of them have for it is bad hope. If hope is generally good, then its opposite must be bad. When questioned about which kind of hope they had been discussing with me, or that they had portrayed in their hope pictures, the answer was always the good hope. The opposite of hoping, for these children, isn't not hoping, or a lack of hope, but rather using the power of hope for something bad.

Curtis and I did not talk specifically about good and bad hope, but he said of hope that "sometimes it's good, sometimes it's bad, like if you hope something happens

and it doesn't happen, that's bad, if a hope happens, then it's good". He too, distinguishes based on the outcome of the hope.

All four children talked of hope predominantly in positive terms. Their own hope, the hoping others did for them, and the hope they have for other children is all positive hope. Good hope is what helps them with their cancer and their fear and pain. But they are not willing to leave the concept hope, or the word hope with only a positive meaning. Perhaps they have not yet been taught that our language only allows for hope to have a positive meaning. Only in having too much of this good hope, do we as adults entertain a possible negative connotation to hoping. Interestingly, the idea of having too much hope, or hoping for something that might be unrealistic was never even mentioned by the children.

It might be argued that hoping for something bad suggests that the children are using the word hope in place of "wishing" or "wanting" something bad to happen. The examples the children used, however, were not about wishes or wants. Bad hoping was not about hoping (wishing) someone loses a game, or hoping (wanting) someone who hit them at school gets kept in for recess. Bad hoping was strictly in the context of personal wellbeing, of getting hurt or of not getting better. Where the good hope is essential, there too is the possibility of bad hope. Perhaps it is only that, a possibility. The children did not refer to it by example or story or picture. They simply suggested that it was possible.

Where The Children See Hope

For adults, things associated with hope have been referred to as hope objects, hope sources, hope bridges, hope images, symbols of hope, hope rituals and so on. These categories seem appropriate to adult hoping, and the way hope is expressed by adults. Jessie, Tyler, Curtis and Michael spoke of hope in words and phrases that could be tailored to these categories, but they don't seem to fit them naturally.

The children referred to hopeful things, but the boundaries between these things was not clear. For example, mother is a source of hope (Curtis), but she is also hope itself (Michael). Dogs are "signs of hope" (Michael), but also sources of hope (Jessie). Rather than categorizing the various things the children identify with, or connect to hope, it seems more fitting to present them as a group. I considered labels such as

"associations to hope", or "hope partners", but they didn't fit with the language of children. When I returned to the children's texts, searching for a phrase or an idea, it seemed that all of these things in which children saw, or felt, or knew hope were things or people or thoughts that helped hope. Although it might be tempting to present the helpers in themes, to do so would be premature. The following list is a sampling of hope helpers.

Hope helpers

dogs	happy thoughts
stuffed animals	relief from pain
family	freedom from worry
friends	smiles
medicine	gummy bears
barley greens	praying
Essiac	"You'll be ok"
garlic pills	"This won't hurt"
vitamins	holding mom's hand
love	trust
angels	hopeful people

Hope is personal

This sample of hope helpers includes ideas from all four children, but it is important to note that each child's hope is unique. Medicine is hopeful for Jessie, but Curtis and Tyler see hope not in traditional treatment, but in herbal remedies. Hope for these children is personal. What it is for them may not be the same as it is for another child. Jessie captures this uniqueness of hope when she says that "hope is like all the same stuff what everybody says it is; what everybody thinks hope is, it is". Tyler too suggests that hope is very individual; "hope is any color you think it is". When Michael and I were discussing whether we had everything to put together a hope book, he suggested that I'd "probably need some other kids' input as well", if I really wanted to know about hope.

For Curtis, hope is not only personal, but quite private. When he admitted that he actually did hope, he made sure the tape recorder was turned off, so that only I would hear him. He also said that "the only thing that helps people hope in the hospital is themselves". Hope is something Curtis says he does alone.

Hoping

At some point all of the children referred to hoping as something they themselves could do, either alone or with the help of someone. Hoping is an activity that you can choose to do. It is intentional, and there are ways to do it. For Michael, hope "comes in your body usually when you think of it". Jessie too "just like thinked in my mind and it happened!" To go about hoping Jessie suggests thinking happy thoughts like a sunny day or going to the beach. Curtis said to "think of life", and then "hope for it". When hoping is particularly hard, Tyler said "I just double hope". Hoping is something the children do, and can do with even more effort when required.

This active deciding to hope or to hope harder has been referred to by Hinds (1984; 1988) in her work with adolescent hopers. Part of the definition for adolescent hope is the concept of "forced effort" (1984, p. 360) which refers to purposely trying to take on a more positive view. This is an aspect of hoping which is "not reported in the literature on adult hopefulness" and which "may indicate that the dimension is unique to adolescents" (Hinds, 1988, p. 87). The way the children in this study talked about hope appears to indicate that forced effort may pertain to hoping children as well as adolescents.

You Don't Just Hope Alone

While hope is something that is inside the children, and hoping is something they can do, "hope isn't something you can just do by yourself, I mean you need other people to be there" (Michael). According to Tyler, hope is both internal and external. "It is all over the place in your body" and also "all around us" (Tyler). Through their own experiences of hope, these children have grasped what McGee (1984) refers to as "a vital dimension of hope. A sense of external helpfulness enhances the internal dimension of hope" (p. 39). Hope does need helpers.

Mom the Hopemaker

Mother was one of the main sources of outside help identified by the children. Other family members such as dad, and brothers, sisters and cousins were also important, but mom was clearly the strongest link to hope. Michael, Jessie, Curtis and Tyler varied in the degree to which they relied on their mothers for help hoping. Michael literally embodied hope in his mother; "when my mom walks out the door it doesn't shatter hope, it just, she walks out the door and when she comes back...it comes right back". Hope comes and goes with his mother.

Jessie identified her mom as her most important hope helper, "because I love her" and "she um doesn't make me worry". When Jessie needed to feel better, the best thing she could do was to cuddle with her mom. Comfort and security for Jessie came from mom. She knew her mom was a hopeful person,

cuz when you get a scratch, or like you hurt yourself alot, and you need to go to the hospital, she'll take you, or if I fall down on my bike, she'll get me and put a bandaid on my knee.

It may be important to note that Jessie's mom stayed overnight in hospital with Jessie during all her admissions, and that Michael's mother did not go home from hospital during his admissions.

Curtis didn't focus his hope so specifically on his mother, but said that she would also be his most important helper, probably because she wanted to get rid of his cancer and gave him vitamins. He also thought that she prayed for him to get better. For Curtis it seemed that it was what his mom was doing and hoping for him that were most important.

Tyler too referred to his mother in the context of her being the one who provided him with his barley pills and Essiac. He did not talk specifically about getting his hope from his mother or family, instead relating more of a spiritual source for his hope.

That the children turned to their mothers for hope, is consistent with the writings of Erikson (1950, 1964, 1977) and Lynch (1965) on the development of hope, which were presented in Chapter II. If it is out of the trusting relationship established with mother in the infant years that children's hope begins to grow, it seems natural that when faced with cancer, a life threatening illness, the children look to "mom the

hopemaker" (Michael). From mother comes comfort, safety, security and love. Perhaps mom can't save me from the cancer, or stop the invasive procedures, but she can hold my hand, get my eye off the needle, make me laugh, tell me it'll be ok and not to worry. With love, reassurance and hugs, mom can ease the pain and renew the hope.

The children talked about hope in relation to love and trust. Both Jessie and Tyler specifically said that hope *is* love, and that that would be the best way to explain it. They gave examples of their family, or God loving them, which made them feel much better. In talking of a color for hope, Michael suggested that hope was "probably red or something like that, red or pink...cuz that's usually a sign of love or something". He put it all together when he said,

if you really love someone, you really trust them too, so it also means that like, that when you when you trust someone, you know that...they're telling you the truth, and telling you it won't be bad, and well, that's hope.

Michael seems to understand that trust precedes or is at least connected to hope.

Erikson (1964) refers to hope as a basic virtue "with which human beings steer themselves and others through life" (p. 115). When the children are forced to cope with cancer, a threat to their life and likely also to their hope, it is understandable that they need to rely on the strength of others in addition to their own. During a time of crisis, perhaps it is the basic needs such as comfort and security that are sought. Rather than being able to continue the normal age-appropriate tasks of psychosocial development, the children are focused on their physical wellbeing and survival. Recent clinical work suggests that in some cases it may be that the children's psychosocial development is temporarily delayed and they remain at the developmental age of initial diagnosis (Michael Handman, Ph.D., personal communication, November 8, 1994). As it was during infancy and early childhood, it is again mother who can fulfill those basic needs.

Due to the complex interaction between illness, crisis and psychological development, chronological age doesn't appear to be a good indicator of the degree of reliance on mother for hope. Indeed, among the children I spoke with, it was Tyler, the youngest, who talked least of his mother in relation to his hope. From what the children said, by report from medical staff, and through personal interactions with the

children and their mothers both in clinic and on the inpatient ward, it was clear that all four mothers provided excellent support and caregiving to their children. Individual differences relating to personal experience with illness and with hope more likely contribute to the varying degrees that Tyler, Curtis, Jessie and Michael linked their hope to mother.

God Has Something To Do With Hope

For each of the children, there was some link to a spiritual aspect of hope. Curtis mentioned that his mother and grandmother prayed for him, and he thought that praying was a good thing, because it was like hope. Michael spoke of God as being able to respond to hope. Jessie recognized hope in the form of an angel given to her by a family friend. Without having to be told, she knew the angel was hope, and said it reminded her of heaven, a place of "love and caring". Jessie thought that the angel probably got her hope from God. "God gives everybody hope".

Tyler seemed the most sure of a spiritual connection to his hope. Hope was given to Tyler by his special spirits who made the hope out of love. There was no doubt in his mind that the spirits were his and were there because God wanted them to look after him and help him through tough times. Whatever the form, all four children expressed some sense that hope was connected to a higher power outside themselves. Interestingly, there were no references to hope being symbolized in traditional spiritual ways such as light or water or the cross.

Whether it is helped by mother, or family, or by a higher power, the children realize that hope is connected to others. In fact they are able to identify hope in others, and also see where it is lacking. Curtis and Tyler talked of the hopeful people in their lives as identified by what they said and how they acted. Michael was able to see lack of hope in the little boy who was left in hospital without his mother. "He probably didn't have any hope, I felt sorry for the guy" (Michael). Just as they rely on others for hope, the children also hope for others.

It's Important To Hope For Others Too

In addition to hoping for themselves, the children expressed the importance of hoping for others, "because there's a bigger chance...that the other person will get

well" (Curtis). Both Michael and Tyler made spontaneous references to hoping for others; Michael for the little boy who had surgery, and Tyler for his Grandpa. "I'm hoping that my Grandpa gets better...he has cancer in his leg" (Tyler). Tyler also said he shared his hope with his friend whose house exploded by accident.

The children's ability and desire to hope for others echoes the findings of Hinds (1988) which indicated that adolescents with cancer hoped for others. Hoping for others was particular to the adolescents experiencing cancer, and was an attribute formerly associated with the developmental traits of adults. Hinds (1988) suggested that "the experience of a life-threatening illness such as cancer may have a maturational effect upon adolescents" (p. 87). When demonstrated in a child only six years of age, namely Tyler, perhaps the hoping for his Grandpa reflects his feeling that hope is so essential to his own "getting through" cancer, that it is important for others too. This is not a finding unique to the four children featured here. As I work on the inpatient oncology ward I see children hoping for each other every day. Please see Chapter IV for the various ways Tyler, Jessie, Curtis and Michael had for sharing their hope. Again, it is clear that how the children share their hope reflects their own experiences and their own hoping.

The Importance Of Hope

"Cuz If You Don't Hope, You Haven't Got A Chance"

That was Curtis talking about the importance of hope. For Curtis, hoping is essential, and while it is something you can choose to do, he couldn't imagine anyone choosing not to. Hoping is necessary if you want to get better. Tyler agreed, saying that "people who were really sick wouldn't get better if we didn't hope that they did". Hoping is important, and makes a difference. "I got through this and it was mostly hope that got me through this" (Michael).

The essential nature of these children's hope resonates with the writing of Erikson (1964) who described hope as "the basic ingredient of all vitality" (p. 116) and saw it as an inner strength necessary for the sustainment of life. Throughout the interviews, the children repeatedly returned to hope in the context of the survival of self or others. Although they referred to everyday hopes such as hoping to get a soccer

goal (Curtis), their focus remained primarily on their hope in relation to cancer and the importance of that hope in getting well.

Hope for these children is about survival. Neither in their hope pictures nor in their personal stories did the children highlight such hopes as getting their hair back, or hoping that they get more presents in hospital, their hope focused on long term well being. "I sorta did alot of hoping that I wouldn't...die" (Jessie). "My hope is that I, I can get through this big tough year" (Tyler). "I hope I get through this" (Michael). "I really do hope I get better" (Curtis). And Jessie, "hoping that I don't get sick again". These children hope to avoid death; they hope for survival, and to not get sick again.

The children are also able to look ahead, past their cancer to a time when they are better. Curtis hoped to play baseball, and he did. Tyler's hope allowed him to look forward to learning to read in grade one and he drew a hope picture of himself "teaching a little kid how to read". Tyler is currently in grade one and he has started reading. Michael spoke of elaborate plans to build a giant sea life kingdom called "Awesome Waters" when he is old enough. As part of their hope, or perhaps because of their hope, the children see for themselves a personal, positive future. Their hope is realistic and possible. They see a life beyond cancer, in which they are well, and happy.

The children's ability to foresee a better future for themselves is again consistent with features of Hinds' definition of adolescent hope. Hinds refers to the "expectation of a better tomorrow" and the anticipation of "positive, personal future possibilities" (1984, p. 360) in defining adolescent hopefulness. Jessie, Michael, Tyler and Curtis clearly expressed aspects of both features.

Disease-Hope

Near the end of our second interview, Michael made an interesting comment that he didn't think "many people are very hopeful about many things". Upon further discussion it became clear that Michael distinguishes between everyday kind of hoping, and the hoping you do when you have a disease, which is a "way different kind of hope" which he referred to as "disease-hope" or "fate-hope" (Michael). Prior to getting cancer, Michael said that he had hope "that he'd have good luck the next day,

just hope-hope, but I never had fate-hope before". Jessie also said that before she got cancer she didn't think much about hope.

That hope is essential becomes apparent in illness. Hope is important, especially when you're really sick. Perhaps this essential quality of hope is partly embedded in illness or other life or hope threatening situations. As Marcel (1951/1965) suggests, hope appears only when there exists the possibility of despair. The children's hope is reflective of this possibility of despair. Their hope pictures all depicted hope needy situations, three of which involved a threat to self by cancer or its treatment. With the exception of Tyler, the children's initial expressions of hope were in the context of illness. Tyler's first expression reflected his hoping that the animals don't die. In their words too, the children expressed the understanding that having cancer is lifethreatening and that hope can help.

Hope Helps With Pain

In addition to aiding the chance of survival, hope was seen by the children to be connected to the relief or endurance of pain. Curtis' hope picture showed a child experiencing considerable pain on the operating table. "That's a time when you really have to hope, when you're sick and it hurts" (Curtis). Jessie was scared when she had her broviac surgery, saying "I hope it doesn't hurt". Michael explained that when his mom was there he had hope, "and it felt good that I could...have hope so that it wouldn't hurt as much". Having hope that a procedure will be over quickly, or having someone tell them it might not be that bad, helps the children with their pain. As Michael put it, "it's like having a friend that could help you with your pain".

It seems that for these children, having hope lessened the pain they experienced. In addition, the relief of pain improved their hope. When Michael's mom held his hand, "that deals with some of the pain and that was hopeful". It seems almost circular; a hopeful attitude reduces the pain, and the reduction of pain enhances the hope. I have also found evidence of this recently when introducing children on the inpatient ward to hypnosis. As they experience successful pain reduction or removal with self-hypnosis, they report having increased hope that the procedure won't hurt so much next time either.

Hope Helps With Fear And Worry

Jessie explained that she needs hope because it "makes me happy and not scared anymore". She talked of the hope that she got from her favorite doctor who "tries to make you sorta don't worry". The hope Tyler got from his spirits helped him "feel better when I'm having a bad time". Curtis mentioned feeling brave, which was part of his hope and made him feel better.

The children make it clear that hope influences whether or not they survive, but it also has to do with the kind of life you have during cancer and afterward. Not only is hope essential to survival and life being sustained, it is also important because it impacts the quality of life. Hope has something to do with attitude. "You actually need hope, if you're actually going to get through something without, well, without being really unhappy and grumpy at the end".

Helping Children Hope

In talking with Tyler, Jessie, Curtis and Michael about hope, I received several important messages.

1. Hope is essential to a child living with cancer.
2. Having cancer and enduring invasive treatment, hospitalizations and painful procedures makes it very hard to hope.
3. When it is hard to hope, children need outside assistance to help the hope that lives inside them.

Having heard these messages, I realized that the words, the images and the wisdom of these four children need to do more than provide hints to hope. They need to impact my work with children, specifically children living with cancer. With that in mind, I offer the following thoughts, for careful consideration and reflection, to health care professionals, parents, family and friends who live and work with children living with cancer.

Uncovering Hope

Hope for children appears to be personal and unique. Children see hope in such varied things as holding their mom's hand, a favorite pet, barley greens, remembering the smile and attitude of a friend lost to cancer, or getting gummy bears from their

brothers. Children also find hope in different ways. Some may connect to hope by touch, others through hearing hopeful words, and still others by reaching out for spiritual help. Wherever they see or find hope, I believe that children know their own hope. They experience it, they know where it comes from, how it helps them and how to share it, but they may need help expressing it.

Because it is so personal, hope may be quite private for children, something they hold deep inside and don't readily show or talk about. Before we can help children hope, we must first encourage the expression of their hope so that we might understand it. In order to understand the hope, we must understand the child. Hope is reflective of the child's experiences, belief systems, ways of coping and of being in the world. Hope speaks of the hoper.

Encouraging the expression of hope requires really listening to the child for hints to hope, creating ways of "talking" about hope with the child, and eventually a gentle uncovering of pieces of hope. Anssi Perakyla (1991) suggests that conversation is the most important tool in hope work, or helping people with their hope. It seems that this applies to children as well. It is through dialogue that hope becomes apparent, and that children come to understand their hope and how it works in their lives. (A particular example of coming to understanding through dialogue is evident in my conversations with Michael regarding hoping and wishing.)

While conversation with children is critical, it is important to remember that our language for hope is limited. The notion of conversation with children must be expanded to include art work, play, story and whatever other means of expression seems fitting for an individual child. It may also be helpful to focus discussions on the child's own hope, rather than general references to something called hope. Children's hope is important to them, and they best know their own hope experience.

Hope Is Something Children Can Do

Children can and do hope. They view hope as an activity that they can choose to do. They have some control over their hope, being able to access, or get it when they need it. They know who and what helps them hope, and they can be intentional about hoping. Hope appears to provide children with an additional sense of control. Perhaps this sense of control increases the children's feelings of mastery over what is

happening to them and enhances their ability to cope with difficult situations and procedures.

Hope helps with fear, pain and worry; it can help children feel like they are more in control over these feelings. Perhaps things like barley greens and Essiac provide an additional sense of control over the cancer, over the part that may not be covered by chemotherapy or radiation. In supporting children in their hope, maybe we need to believe that the children know best in regard to their hope. The children are their own hope experts, and only by learning of their hope, can we encourage it.

Responding To Hope

Hope authors and researchers suggest various ways of instilling hope (Limandri & Boyle, 1978), sustaining or maintaining hope (Dufault & Martocchio, 1985), refocusing hope (Hinds, 1988), inspiring hope (Miller, 1989), and enhancing hope (Jevne, 1991) in others. These terms seem fitting in relation to adults, but in relation to children, I prefer to stay closer to their language and talk of helping hope. Based on this exploration of hope with Jessie, Tyler, Michael and Curtis, I have come to think that perhaps children don't need their hope enhanced, or inspired, as much as they need it responded to.

Once children begin to express their hope, we need to listen carefully so we can respond to their expressions. If hope is seen by a child in things like vitamins or barley greens as it was for Curtis and Tyler, perhaps it would be helpful to validate to the child that hope in things beyond treatment is okay, and need not be thought of as an extra, but as another essential to that child's treatment. When a child expresses a specific hope helper such as a "doctor who would stop by not to do something, just to talk", then an appropriate response might be to try to increase the number of times that the doctor stops by just to chat, even if only for a minute or two once a day.

If a child suggests that she draws hope from a family pet, as Jessie did, it might be helpful to incorporate the pet into as much of the child's day as possible. Pictures of the pet could be placed within the child's view in hospital, and if possible, even a short visit could be arranged outside hospital doors if the child is well enough to venture off the ward.

I am currently working with a six year old girl who identified her little white dog as one of her hope helpers. We have incorporated "Sparky" into her favorite self hypnosis which she uses during lumbar punctures. I also refer to Sparky during therapy sessions, suggesting that he must be waiting for her to get better and come home, or we talk of how good Sparky makes her feel, and how thinking about him helps her to be happy. Even though this little girl has been very sick from chemotherapy and unable to talk or eat due to excruciating mouth sores, when she hears Sparky's name, her eyes light up and a small smile comes across her lips despite the pain it causes. It is easy to see the hope that Sparky brings to her.

As the children in this study indicated, family is essential to hope. This is an important consideration in responding to children's hope. Once the ways that family helps a child's hope are identified, there is much that can be done to support that help. Encouraging parents to stay in hospital when possible, and fostering meaningful involvement in their child's treatment may be helpful. In small but important ways, parents can be shown how to become coaches or partners with their children to help them through uncomfortable procedures or difficult times in hospital. If children are identifying their parents as hope helpers, the parents need to know, and be encouraged to explore that role to its full extent.

Responding Hopefully To Children

It is important to respond or act hopefully toward children, specifically those with lifethreatening illness, who may look to us for hope. Michael, Jessie, Tyler and Curtis demonstrated that children can identify not only their own hope, but hope, or the lack thereof, in others. They link hope to people they love and trust and can believe. They see hope not just in what we do, but who we are. A smile, hopeful words, a hopeful gift, however small, may make all the difference.

In my work on an inpatient unit I have found that if I can help a child make some positive change, perhaps helping him gain control over nausea for a few hours, that a bond between us is established quickly, even on a first visit. The children express a sense of hope that if they can help themselves once, then they may be able to do it the next time too.

Responding hopefully involves being honest with children, yet conveying a positive, hopeful attitude that implies confidence in their abilities to help themselves. A good example might be in responding to a question such as "Is this going to hurt?" A hopeful response might be to say that "This can hurt, but I think that together we can stop alot of the hurt, maybe even all of it". Such a response is consistent with what the children indicated were hopeful messages for them, such as hearing from mom that it won't be so bad (Michael), or having a doctor tell them that they were doing very well and were getting better (Jessie).

Children know hope and hopeful people when they see them. For this reason, we need to reflect on our words, our actions and our relationships with children in the context of what we know about their experience of hope, so that we may be on their list of hope helpers.

How Different Is The Hope Of Children?

Part of our reflection might include a look at just how different we think the hope of children is from our own. That children are born with the capacity to hope, and begin to hope early in life as a result of a trusting relationship with their primary caregiver, is documented in the writings of Erickson (1950, 1964, 1977) and Lynch (1965). It is also generally accepted that hope is developmental in nature, although its course of development, and the factors involved have not been clearly specified. Wright and Shontz (1968), as a result of their study which included questioning physically challenged children and adolescents, suggested that children's hope is clearly different from the hope of adults as it lacks orientation to reality and is therefore considered closer to wishes or desire. They did not indicate when children might have enough reality surveillance to actually hope.

Based on the conversations I had with Curtis, Jessie, Tyler and Michael, I have no doubt that these children hope, and that their hope is based in reality. Perhaps it is because of the stark reality with which they have been faced, namely their cancer, that they hope as they do. Yes, these children have more thinking to do about the difference between hopes and wishes and desires, but maybe we as adults should also think more about those distinctions. The children demonstrated to me that they know

the difference between reality and fantasy, and that wishes belong together with geenies in the realm of fantasy.

I no longer entertain the idea that children's hope can be distinguished from adult hope on the basis of lacking a reality orientation, at least not in children over the age of six. Even in younger children I wonder how helpful such a distinction can be. If we are to help children hope, we need to understand hope from their perspective and respond to the personal hope that they express, using their words and images. If I approach children wondering whether or not they have the capacity to hope, or know the difference between hoping and wishing, I can not possibly approach them hopefully, much less offer them any help.

Since the work of Wright and Shontz (1968), very little research has been conducted specifically with children. Adolescent hope, however, has been studied in depth from a qualitative perspective. Given that children and adolescents are at different developmental levels psychosocially, the findings have not been linked to children's hope. Interestingly, the hope explorations that the children and I took together did not reveal anything that would make Hinds' (1984, 1988) definition of adolescent hopefulness inappropriate for Jessie, Curtis, Tyler or Michael.

The definition states that adolescent hopefulness is "the degree to which an adolescent possesses a comforting or life-sustaining reality-based belief that a positive future exists for self or others" (Hinds, 1988, p. 85). The four children I interviewed were ages six to nine, yet their experiences of hope seem to fit well with the adolescent definition. The children did not express aspects of hope or hoping which were inconsistent with the adolescent definition.

Connecting To The Hope Of Children

Each of us working with children living with cancer has to come to our own understanding of children's hope, and how it does or does not relate to our own capacity for hope. Throughout my explorations with these children, I have pushed my own hope into the background as I concentrated on the hoping of children. I realize now that this happened largely because as I studied hope in these children, I was forced to either confront the nature my own hope or put it aside so I wouldn't have to.

It was not until our hope explorations were over that I faced my own hoping. Late one evening when I arrived in Vancouver at my parents' home for a surprise visit, my mom explained to me that she was scheduled for major surgery as a result of ambiguous medical test results. We talked for an hour or so before going to bed. As I lay in bed that night, going over what my mom had told me, I found myself hoping. My eyes were shut tight, and I was concentrating hard, willing everything to be alright, praying that my mom would be okay. I was grasping at ideas, thoughts, sensations, anything that would bring strength, perspective, a positive outcome.

Earlier that day I had been reading the transcripts of Tyler's interviews, and my mind flashed back to what he had said about "double hope" and how it was done. I recalled his words about trying "to find more hope" and "sorta asking your body, you're you're trying to think, but you don't say it, you're sorta telling your body to suck in some hope...cuz hope is all around you". I couldn't have described it better. And then I knew that how I hope is not so different from Tyler's, or from that of the other children. My words may be more sophisticated, and I have my own symbols, images and hope helpers, but it ultimately feels the same. That is a learning I hope I never forget, and that I hope will go with me as I meet each new child.

Pieces Of Hope

Exploring hope with four children living with cancer allowed me to see hope through their eyes, and to glimpse how hope lives inside of them. I do not, however, have answers, or conclusions. Had I talked with forty children, I would still not have the final word. What I have presented is what the children gave me, what they have experienced and felt to this point in their lives. Their ideas are rich and full, yet even combined they offer us only pieces of hope. I am beginning to believe that perhaps that is as close as any of us will ever come to understanding hope. Perhaps that is part of the understanding. Perhaps it is part of hope.

Lingering Curiosities

Having completed this beginning hope research with children, I am left with additional ideas and wonderings, which might be the genesis of further research.

- How do healthy children experience hope? How might their hope be the same or different from children living with cancer?
- What would I learn if I followed one child and his or her hope through the experience of cancer, beginning at diagnosis and continuing through treatment?
- What could children's hope drawings say to us if we viewed them through the lens of projective analysis techniques?
- What is hope for the parents of ill children? How does it influence or reflect itself in the hope of children?
- What is the relationship between hope and play?
- How might I further explore the importance of family to children's hope, to provide insight into the contextual factors which influence hope?
- Based on the ideas of children, might it one day be possible to begin generating a theory of hope?
- What is hope for children who are younger than 6? How might we uncover their hope?
- Based on this research, how might I better weave hope into my work with children?

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Appendix A

Exploring Hope With Children Who Are Living With Cancer

CONSENT FORM

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose and Description of Study:

The purpose of this research is to explore hope from the child's point of view, specifically the child living with cancer. By sharing their experiences of hope, the children will allow caregivers to help them use hope in coping with cancer.

Your child will be asked to explore hope by drawing pictures and storytelling, as well as by discussing hope with the psychologist. Possible interview methods include questions such as the following: 1) Describe or draw a picture of hope. What does hope look like? Is it an animal, a person, or a place? Where is it? 2) A child from another planet comes to visit you. She doesn't know what hope is, they don't have any on her planet. How would you explain it to her? The children will not be asked about their experience with cancer, but will be allowed to share their experiences if they start a discussion about cancer.

Your Child's Involvement:

You will be contacted a few days after you receive this form to give you and your child some time to think about the study. The investigator will discuss the study with you and answer any questions you may have. If you allow your child to participate in this study, a time will be set for your child to meet the investigator at the Name of Hospital, or at another place that is convenient for you. Your child will meet with the investigator on two occasions during approximately a one month period. Interviews will be recorded (audio-taped) and although interview lengths will vary, it is anticipated that they will be approximately one hour long.

Your child can refuse to answer any question during the interview. Your child's physician at the Name of Hospital has consented for your child to participate in this study if you and your child agree.

Your child's identity will remain strictly confidential and will not be revealed on any transcript, art work or reports resulting from this study. Another name (pseudonym) selected by your child will be used in all transcripts. All data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

Participation in this study may be of no personal benefit to your child. However, based on the experiences of other people involved in similar types of research projects, your child may derive benefits such as support and validation of his/her experiences. It is also possible that, based in part on the results of this study, health care professionals, parents and children themselves might better understand hope and its importance to children experiencing cancer.

Understanding of Participants:

My signature on this form indicates that I have understood to my satisfaction the information regarding my child's participation in the research project, and agree to let my child participate as a subject. In no way does this waive our legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I am free to withdraw my child from the study at any time without jeopardizing his/her health care. His/her continued participation will be as informed as my initial consent, so I am free to ask for clarification or new information throughout his/her participation.

I understand that Susan Danielsen at 437-1671 or Dr. Name (Director of Psychology) will answer any questions that I have about the research project.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that my child and/or myself have been encouraged to continue in this study beyond our wish to do so, I can contact the Patient Advocate at phone number.

A copy of this consent form will be given to me to keep for my records and future reference.

Name of Parent or Guardian

Signature

Name of Witness

Signature

Name of Investigator

Signature

Date

Appendix B

Hello,

My name is Susan Danielsen, and I am an intern at the Name of Hospital in the Department of Psychology. I am also a chartered psychologist in the province of Alberta and a doctoral candidate at the University of Alberta. As part of my doctoral degree, I am researching children's understanding of hope. I chose to research children's hope as a result of personal and professional opportunities to interact with children who are experiencing illness.

Current psychological and medical literature suggest that hope is essential to children living with cancer, yet no one has asked children what hope is, or what it means to them. The purpose of my research is to explore and present hope from the child's perspective, specifically the child living with cancer. These children literally embody hope, and I believe that they have much to share with us about how we might better help them sustain or enhance that hope and use it to help them cope with cancer. I also feel that the information shared by children about hope will be helpful to other children as well as to helping professionals who provide services to children with cancer.

Thank you for agreeing to read the consent form and to consider allowing your child to participate in this research. If you are interested in this research, or have any questions, please leave a message for me at phone number (Department of Psychology). I hope to speak with you soon.

Sincerely,

Susan Danielsen

Appendix C

INTERVIEW GUIDE

I intend to invite children to explore hope through drawing, pictures, or story, as well as through dialogue or interview. Experience with children in educational and therapeutic situations has taught me to initially encourage children to express themselves nonverbally. Once children become engaged in a nonthreatening, enjoyable activity, they are more likely to express their thoughts, feelings and experiences verbally as well. Used together in an interactive way, art and dialogue can provide rich information about children's worlds.

While following a general set of possible inquiry techniques and questions, the interviews will be spontaneous and allow the children to freely express themselves. Below is a sample of techniques I have compiled to date. I anticipate that, based on interviews with the children, new questions and approaches will be added as needed. "Although general questions may be formulated in advance, genuine dialogue cannot be planned" (Moustakas, 1990, p. 47).

Possible Interview Techniques

- 1) Describing or drawing a picture of hope. What does hope look like? Is it an animal, a person, or a place? Where is it? What color is it? How big, or small - what size is it?
- 2) A kid from another planet comes to visit you. She doesn't know what hope is, they don't have any on her planet. How would you explain it to her?
- 3) A friend of yours needs some hope - and you want to help him. You want to give your friend a "hope kit"(R. Jevne, personal communication, May 4, 1993). What would you put in the kit? What would you leave out of the kit? When would you give it to your friend?
- 4) Think about someone who you feel is really hopeful. Tell me about that person. How can you tell they are hopeful?
- 5) Sometimes hoping is hard. Tell about a time in your life when it was hard for you to hope. What made it hard? Who, or what got in the way of your hope? What helped? How did you hope even when it was hard?

6) Tell me about your hope. What does it mean to you? Where do you get it? Do you always have the same amount? Who helps you with your hope? Can you share it? How? With whom?

Appendix D**DEMOGRAPHIC DATA**

Pseudonym _____

Gender _____

Age _____

Grade _____

Child's Diagnosis _____

Date of Diagnosis _____

Treatment History and Dates

Prognosis (if known)

Family Description (parents, siblings)

Appendix E

Audit Trail

Project Title: Exploring hope with children living with cancer.

Investigator: Susan Danielsen, M.Ed., C.Psych.
Ph.D. Candidate

I. Proposal Development

Sept. 1992 - Apr. 1993	Course work in hermeneutic phenomenology Project Title: Pieces of Hope Reading hope literature
May 1993	Pilot work exploring hope with a regular grade 5 class
May - July 1993	Development of research question and proposal
Sept. 1993	Begin doctoral internship working with pediatric oncology patients Candidacy exam completed Reading pediatric oncology literature
Nov. 1993	Approval of hospital pediatric team Submission to hospital ethics committee
Dec. 1993	Clinical priorities committee approval Educational Psychology Research and Ethics Committee approval
March 1994	Hospital Research Ethics Committee approval
1992 - 1994	Hope Research Group member at The Hope Foundation

II. Selecting Participants

April 1994

Obtain audio-taping and art work materials

Direct contact made with Tyler, Curtis and their parents for consent to participate

Asked nursing coordinator to distribute cover letter and consent form to children and parents

Contact made with Jessie and Michael

III. Data Collection

Apr. - July 1994

Hope explorations with the children

Tyler #1. April 25, 1994
 #2. June 13, 1994

Curtis #1. April 29, 1994
 #2. June 13, 1994

Jessie #1. June 13, 1994
 #2. July 20, 1994

Michael #1. June 10, 1994
 #2. June 21, 1994

Researcher observations, notes and memos continued throughout this phase

Personal transcription of audio tapes into text within 24 hours of each interview

Indentification of preliminary themes from first interviews and discussion with participants

IV. Data Analysis

July - Oct. 1994

Comparison of audio-tapes to transcripts

Reading and rereading of texts; immersion into the data

Analysis and interpretation of each child's hope exploration

Themes identified from each child's exploration

Comparison of themes among all children

Second review of literature and comparison with children's ideas

Discussion of findings with professionals in the fields of hope research and pediatric psychooncology

V. Presenting the Results

Nov. - Dec. 1994

Verifying themes and reflections with original data

Searching for discrepancies

Writing and rewriting of Chapters IV and V.